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TOWARDS A THEOLOGY OF PERSONHOOD: THE GIFT OF THE ALZHEIMER CHRISTIAN AS A WAY OF RE-CONNECTING OURSELVES TO GOD, THROUGH WHICH THE RECLAIMING OF THE GIFTS OF THE CHURCH CAN ASSIST US.

BY

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Chapter One

My journey of ministering to persons with Alzheimer's disease began several years ago in my former parish of St. Philip's Anglican Church on Vancouver Island. There I had the privilege of making a wonderful connection with John, a gentleman in his early 70's. John was first diagnosed with Alzheimer's disease in the early months of the year 2000. When I first met him he was able to make many normal transitions in life such as looking after his personal needs and remembering specific incidents regarding his family. As his disease progressed, however, some of the ordinary moments in his life became more difficult. He was starting to wander around the house for no apparent reason. His moods also began to change, and the once quiet and reserved gentleman began to have frequent outbursts of anger. John now needed to have someone with him whenever he left the house. Basic errands were 'basic' no longer. As things began to worsen, John's wife found she had to keep a close eye on him so that he wouldn't unknowingly cause harm to himself, like leaving an element on in the kitchen stove, for example.

Naturally, John's wife became more and more concerned about his condition and, after three years of providing the best possible love and care for her husband, she became resigned to the fact that he needed more care than she could handle. He was eventually put into temporary care in hospital for observation and diagnoses. Six months later he was placed in a local extended care facility in the city of Nanaimo on Vancouver Island where he would be able to live out the rest of his life in relative comfort, receiving the care that he required.

It was at this point that my ministry to John took a rather unique turn. I began making bi-weekly visits to him in his new home, and on these occasions I would, after a brief conversation, offer either a concluding prayer or, on occasion, I would give him Holy Communion. As both John and his wife were active members, I knew that John would have some degree of familiarity with the Eucharistic service so, when I offered him communion, I decided to use the older, more familiar rite from the Canadian Anglican Book of Common Prayer. In this particular order of service there is the phrase the priest says at the point of giving the consecrated bread, "the body of our Lord and Saviour Jesus Christ which is given for thee, preserve thy body and soul unto everlasting life, take and eat this in remembrance that Christ died for thee, and feed on him in thy heart, by faith, with thanksgiving".[i] In the same way, when the communion wine is given, the priest says the following words, "the blood of our Lord and Saviour Jesus Christ which is given and shed for thee, preserve thy body and soul unto everlasting life, drink this in remembrance that Christ blood was shed for thee, and be thankful". [ii]

On nearly every occasion, whether John had received the sacramental ministry of the Eucharist, or prayer for that matter, I noticed a change. These familiar words seemed to bring him, albeit temporarily, out of his Alzheimer's state and back into the real world. Something in John's condition changed. It could only be described as some form of an "awakening". This awakening resulted in a noticeable "glow" on his face and, in the case of receiving the Eucharist, an audible response of a series of repetitions of the word "amen". Reflecting on those experiences with John, I have come to recognize that similar behaviours are exhibited whenever various forms of ministry are shared with persons with

Alzheimer's disease and dementia. When I lead worship in an extended care home using gifts such as prayer, the Eucharist, forms of music and human touch - a shift happens inside them. Those seemingly 'lost' appear to be more aware of their surroundings, graced with moments of awakening through long held faith, when otherwise they would not be responding.

I must admit that this concept of an "awakening" came to me from another source - the prominent neurologist, Dr. Oliver Sacks and the findings in his treatment of patients who suffered from Parkinson's disease and encephalitis lethargica in the early 1960's. He believed that his patients were very much *alive* inside even though they showed obvious signs of being in a comatose-like state. Some of his patients hadn't moved in decades, particularly those who contracted the sleeping sickness disorder which was rampant in the early 1930's. I have come to admire the compassionate work of Dr. Sacks. He observed that by supplementing collaborate drug treatment alongside forms of human contact, love, touch, and music he was able to bring his patients out of their sleep disorder into brief periods of an awakening. He noticed a type of change and a transition within his patients. He believed that his patients were still fully human, in spite of their physical impairments - humans who could still be reached by the playing of a particular piece of music or the touch of a human hand.

I have found the work of Dr. Sacks to be invaluable to my ministry to people with Alzheimer's Disease dementia, like my friend John. It seems that there is maintained a very obvious "inner power" that is associated with the many and varied gifts of the

church that have a way of connecting with God on a very deep level. Though stricken, these people remain hosts to the Divine. Many of my colleagues have shared similar personal experiences and observations when doing ministry in hospital and nursing home settings. They have noticed where the power of the Eucharist, prayer, human touch, music and the Word, has initiated some form of transformation whenever residents are receiving these gifts. One colleague in particular remarked that when he went to give the Eucharist to someone who was in a medically diagnosed coma - at the moment the sacrament was brought to her mouth, she immediately awoke. His own experience was one of complete awe at what he saw happening.

There have been other common observations made with respect to the benefits of active ministry in nursing homes in regards to persons with dementia and clinically diagnosed levels of Alzheimer's disease. Over the years, many colleagues have had similar experiences with their parishioners as I did with John whenever The Lord's Prayer is said, or whenever a familiar hymn is sung during worship. Ordinarily, those who would not make any verbal response in normal conversation, would suddenly be able to complete the Lord's Prayer without incident, and have an easy recall of the words of some well known hymns. For one brief moment, it is as if the gifts of the church, and the power behind them, connect with people in such a way that they are once again residing in a familiar world.

These observations open a window of opportunity through which we can explore the deeper question of what it means to be alive and fully human within the Christian

context, especially with regards to persons who happen to have entered the world of Alzheimer's Disease and other forms of dementia. It allows us to begin a journey in the discovery of a Theology of Personhood. It is a very difficult, if not daunting, task to try and create a 'criteria' for an authentic understanding of what it means to be human. I believe to do so would lead to a model of exclusion that would run the risk of suggesting an essence of humanness based on peoples' development and abilities. Dr. Stanley Hauerwas, a leader in the field of Christian ethics, suggests that any form of categorizing people on the basis of their abilities can easily lead into treatment which is inhumane. One can not make a reduction of people into a criteria. To be human in this sense "is to be open to the call of what we are not, and there is therefore no chance that our humanity will be enhanced by excluding from our ranks those who we do not understand as 'we'." [iii]

But how do we even begin to ask, "What does it really mean to be human"? This question is one which has haunted humanity for centuries. One wonders, with the ever increasing technological dependency of modern society, if classic Christian theology and its rich traditions even has a voice in this debate. I believe that it does. We know, for example, that the very question of our identity as human beings within the Christian context began being asked in the Biblical stories of Genesis. Here, in the very beginning of our traditions, we discover the unfolding of God's plan for humanity as a people who have been created in God's image and offered access to the rich diversity of creation throughout all of the stages of life. Ours is a theology that reminds us of who we are in our connectedness with God. Many have given a great deal of thought and reflection to

how God, in His created order, connects with those He loves. We may, for example, think of the way in which God's word come to life in Jesus himself. His whole earthly journey, it seems, was to connect people to the greater reality of what God was doing. How God was able to visit the earth in human form, for example, in order to become intensely close to people's situations and experiences. In the Christian context, we are human specifically because God wants to connect with us.

If we were to look closely at some of the specifics of Jesus' own ministry it becomes particularly obvious that this sense of connectedness was at the centre of the lives he tried to touch. His focal point, was to connect with the brokenness of the world, where peoples lives had become shattered through all manner of sickness and disease of body, mind and spirit. The Gospels suggest that Christ spent at least two thirds of his ministry healing, curing disease, and meeting with those on the fringe of society. The quality of being human was denied to no one. Every person Jesus connected with was treated as unique and valued as if, at the moment, they were of sole importance. It was in their lives that he wanted God's love to intervene. He wanted to give them the assurance that their search for meaning was securely in the hands of God. Marianne Hicks, in her book, "Our Search for Identity", offers this answer for our question "What does it mean to be human?" in relation to Christ's method of ministry, "our connectedness with God is embraced with the very virtues of incarnation, wholeness, and uniqueness." [iv]

Hick's work, I believe, gives us tremendous insight into what it means to be human, as does the work and words of several classic writers of the church's early history. One may

easily spend several years on this endeavour, but for our case it may be helpful to consider, briefly, the thoughts of St. Augustine of Hippo, a man who wrestled personally with this question. History reminds us that as a lead up to the time of St. Augustine, the church had many prominent figures who tried to gain a deeper understanding of the human soul or "psyche" in terms of its relationship with God. Tertullian, in the latter part of the first century, to give one example, wrestled with the idea that the soul was somehow connected with each newborn person and it remained with them throughout their entire life. In his view, however, the soul itself was produced by the child's parents. In the latter part of the second century, Origen suggested that the soul was somehow 'pre-existent' before it came into the life of an individual. When St. Augustine eventually began his search for the meaning of what it was to be human, he did so under the influence of several schools of thought that were in play at the time. His own reflections led him to many years of asceticism in order to ponder more deeply these suppositions. During this period of reflection, Augustine found himself in a tremendous inner search for meaning in life in the midst of everything that he had experienced thus far. His primary search had to do with a sense of separation that he felt between the soul and God. It seemed could the two could not be unified as one because God was not in control of the things that human beings were choosing to do.

It was obvious that St. Augustine was very unsettled by some of his own reflections and conclusions. He was not happy with the path his life was taking. Furthermore, as his own personal story unfolded he became increasingly aware of God's presence in his own journey and his own search for meaning. He realized that, in spite of his own dilemma,

the question of what it means to be human was really a dialogue between humanity itself and God. In one of his essays Augustine describes the difficult path he trod in his search, "I panted for honours, for money, for marriage, and you were laughing at me. I found bitterness and difficulty in following these desires, and your graciousness was shown in the way you would not allow me to find anything sweet that was not you... Let my soul long to you now that you have freed it from the gripping birdlime of deadness. How unhappy it was then! And you pricked it on the quick, so that I might leave everything else and turn to you... I was unhappy indeed, and you made me really see my unhappiness". [v]

These reflections illustrate the honest struggle of a man searching for answers to some of the deepest questions in life. Interestingly, St. Augustine never fully resolved his dilemma, but he did come to believe that there can be no separation between humanity and God. In many respects the work of St. Augustine is typical of the universal search for meaning that has been a part of our dialogue for several millennium. What he does, I believe, is give us permission to continue that search, keeping God always at the centre. This is precisely where the church is in terms of its search for a deeper understanding when members of the faithful succumb to such paramount disorders as Alzheimer's disease and other forms of dementia. All we know is that it is a journey where God is at the centre. Furthermore, what it also does is to allow us to enter more deeply into a dialogue based on the classic teaching of the Christian tradition - that which remind us we are under the umbrella of God's grace which validates our humanity throughout our entire life's journey, regardless of any imbalance or impairment.

Other writers have come forward to offer their own understanding and criteria in an attempt to shed light on this mystery of what it means to be human. Some come across as seeing things very differently from earlier traditions of Christian thought. From a purely biological perspective the work of Joseph Fletcher may be viewed as one offering just such a different perspective. In the early 1970's, Fletcher designed an entire biomedical profile with which to establish grounds for determining what it means to be human. In this profile, he calculated that there were some 15 positive and 5 negative proponents that made up 'being human'.

> "To be a man we must be capable of self-awareness, self-control, have a sense of time, futurity and past, be capable of relating to others, show concern for others, be able to communicate, exert control over our existence, be curious, be open to changes, have proper balance of rationality and feeling, and have a unique identity. Negatively, men are not any of the following: anti-artificial, essentially parents, sexual, worshippers, or a bundle of rights".[vi]

In light of current classical thought one might conclude that Joseph Fletcher's design of biomedical profile seems very dated and almost archaic. Certainly if one isn't from the scientific community, this conclusion could be somewhat challenging. Before dismissing his work altogether, it should be acknowledged that some of his work may serve as a vital component in providing physicians with a model on which to build an *objective* point of view whenever making a clinical diagnosis. Any qualified physician might make the argument that something has to be labelled in order to ascertain which measure of treatment is necessary. It would be impertinent not to consider all of the facts before any treatment or therapy should begin. On the other hand, some of Joseph Fletcher's conclusions, which are drawn solely from the scientific tradition, make rather strong

assertions that being human is somehow *determined* by specific, measurable, factors in the human condition. These conclusions may challenge other non-scientific perspectives; particularly in regards to Fletcher's findings on what denotes humanness. It would seem that the door is left wide open, at least from the scientific perspective, as to what limitations impact personhood.

Let us expand this dialogue by considering the extensive theological reflective work done by Dr. Hauerwas in his ministry to persons suffering various forms of mental retardation. In his own exploration, Hauerwas suggests that the insight of Joseph Fletcher predetermines that these persons are less than human on the grounds that they would fall outside of his criteria model. It appears that Fletcher believes that the critical variable is a minimal intelligence function provided by the neo-cortex. If something is lacking in this area, however, 'being human' becomes questionable. It's obvious that someone who has dedicated so much of his life in the area of working with the disabled, would honestly wrestle with some of Fletcher's assertions, particularly as they dismiss all other aspects of personhood for those living with cognitive disabilities. They have no chance at ever being seen as a part of the human family. In Joseph Fletcher's own words, "any individual who happens to be below the standard intelligence quotient (I.Q.) of 40 in the Stanford-Binet testing is 'questionably a person', and if you happen to score 20 or below you are not a person". [vii]

Dr. Hauerwas' reflections of the challenges presented in Joseph Fletcher's work are born out of a theological perspective. They invite the faith community to take a critical

look at how it views humanity in the light of such viewpoints. In so many ways Fletcher's scientifically drawn conclusions are a drastic departure from the classical teachings of Christendom; the commitment to minister to all people, as affirmed by Christ himself when he said, "I have come that they might have life, and have it abundantly'." (*St. John 10:7-10) NRSV.* On the other hand, one cannot dismiss the scientific world out of hand. It reminds us that truth that is being sought from a variety of perspectives and fields of study. Fletcher's work may very well be a search for the understanding of the human condition based on the inner workings of the mind as they relate to the placement of being "normal" in society. The search via the theological perspective, the one that calls to me, is a much broader endeavour; one based on experience with specific reference to those who have entered the world of Alzheimer's disease, and how that relates to the totality of God's love in a person's life.

In the case of my experience ministering to my friend John, it would be an interesting exercise to see where he might fit in, in terms of Joseph Fletcher's criteria model of the biomedical profile. My guess is that he would fit very few, if any, of the required categories. His advanced Alzheimer's disease would preclude him from being capable of self-awareness, self-control, having a sense of time, having a sense of understanding with regards to future or the past, or be capable of relating to others in any 'normal' way. By this definition John ceases to be human, bringing to light some of the tensions that are a part of the ongoing dialogue between the scientific and the faith communities. Perhaps the question here is not so much about determining the essential criteria to declare whether or not another is in fact *human*, but, as Dr. Hauerwas suggests, "being able to

preserve and enhance what humanity we have. In other words, the question of the criteria of the human should not be raised about others but only about ourselves". [viii]

One way of bringing additional light to the subject is to return to the insights of St. Augustine. Before the end of his life Augustine concluded that all of life is a measure of our humanness. We bring together a compilation of all of our experiences which continue to be a part of who we are in all of life's stages. St. Augustine may very well be saying "our humanness never leaves us, it is begun, continues and ends with the living God". To my mind we have been given an incredible gift in terms of his reflections. I believe he has also given the faith community a deeper understanding of how our sense of identity is connected with our memory, and our ability to relate to all of life's events and experiences. In one of his most celebrated writings, entitled The Trinity, St. Augustine asks the question 'what is it that determines our sense of identity in the world?' St. Augustine cited the example of persons suffering from forms of amnesia. It was assumed that the individual with amnesia was somehow stranded in a present without a past, and that such a person has no memory. An undamaged memory supplies us with an endless array of how we view ourselves and the world. It is where we can not only remember certain aspects of our personhood, but where we can also view ourselves in the same light as might an observer. As St. Augustine himself puts it, "this is where I bump up against myself, when I call back what I did, and where, and when, and how I felt when I was doing it. This mystery of being both the observer and the observed finds in it a trace of the way God is 'in God's company in the Trinity". [ix] It could be said, then, that being unable to remember is a threat to our identity and, by association, our personhood, our

being human.

It could also be said, therefore that memory, then, also plays a very important part in how we make the connection between ourselves and God. Such memory, according to the work of noted theologian Dr. David Hogue in his book entitled Remembering the Future, Imagining the Past, helps in the retrieval of some of the basic qualities in life which everyone should enjoy. According to Hogue, "this is where we are able to reconnect with those episodes or events that are part of our stories and make sense of who we are, where we have come from and perhaps just as important, where we are headed".[x] Thus, memory and identity may be seen as going hand in hand.

Yet, for our own purposes and reflection, St. Augustine also allows us to see where this connection between memory and identity becomes such a vital component in our ministry with those suffering debilitating forms of memory loss such as Alzheimer's disease. For them, their very identity, "who they are" and the catalogue of all of life's episodes and experiences are at risk. Their memories, at best, are a configuration of jumbled thoughts and images. It is at this very point where the church can once again offer its gifts by coming alongside the individual and, making a "holy intersection" of ministry through communal memory; allowing that person a deeper connection with God. I believe this is what may have been happening to John during the course of my pastoral ministry to him and when the gifts of the church were offered to him. They were building a bridge to all of those things that were important to his inner being, reminding him and us that he was still a part of the Christian community, and of God's plan of salvation. To

my mind this was, in essence, was his "awakening".

John's "awakening" while receiving the sacrament became, for me, a call to deepen the search for ways in which pastoral ministry might provide a model that would allow persons with Alzheimer's disease, and other forms of dementia to experience a deeper sense of God's presence in their lives. Are there specific forms of ministry and liturgical practices, for example, that are more helpful in making connections with persons with brain impairment and dysfunction? Are there specific hymns and scripture readings that are more helpful when conducting a service? As a practitioner in ordained ministry, I believe these questions are critical, not only to providing an appropriate liturgical framework for this particular model of pastoral care, but as a reminder of our mandate as Christians to love one another, following Jesus' example.

In many respects this exploration is a direct result of some of the realities currently facing North American society. Many of the "baby-boomer" generation are now reaching retirement age and meeting some of the situations associated with "growing old". We can safely assume that there will be more cases of persons suffering from Alzheimer's disease and other forms of dementia. We can further assume that our nursing homes will be occupied with more cases of people searching for meaning and identity in their world of 'jumbled memories and experiences'. Yet this searching doesn't have to be one of pessimism as people enter into the world of this disorder. Instead it can be one of hope as we embrace the humanity that has been with us all along and remains with us, in spite of this disorder. Furthermore, it can be a journey full of possibility for all of us as we

assist our brothers and sisters through the rediscovery and reclamation of the power of the gifts of our beloved church, and a reconnection with God to gain a deeper understanding of our selves and what it means to be human. Therefore, let the journey begin.

Chapter Two

As we probe deeper into our understanding of the nature of personhood regarding individuals with Alzheimer's disease, it would be wise of us to take a brief clinical overview of the characteristics and progress points of Alzheimer's disease and age related dementia. Any reflection of this nature must begin with some basic assumptions around memory and forgetfulness and what is considered "normal" in the aging brain. All of us, at one time or another, have experienced a certain level of forgetfulness or even the occasional, brief memory lapse. We have all misplaced, for example, the car keys, or we have forgotten to pick something up when we were at the grocery store. When this happens, we can justifiably trivialize the event confident that this is merely a temporary misjudgment on our part and can carry on with the rest of our daily routines. These minor episodes have no significant impact on our lives as, generally speaking, our entire life - span includes these types from time to time. The medical profession refers to this condition as "benign forgetfulness" and, although a majority of the population experiences it to some degree, the causes are unknown. We all understand this facet of everyday life as being "normal". Studies also indicate that as people get older there is often a "natural" forgetfulness in some individuals, but even then, as the prominent neurologist Dr. Daniel Kuhn reminds us, "the common forgetfulness associated with aging may be more typical or "normal" in that the majority of older people experience this to a degree". [xi]

We can all think of persons who are aging who show little, if any, difficulty in areas

regarding memory and forgetfulness. We marvel, for example, at people who in the later stages of life, still have very acute, sharp memories and who appear to have no difficulty whatsoever recalling both present and distant events. Up until a few years ago, the Hollywood personality, George Burns, amazed his fans with his ability to carry on his work as an entertainer with relative ease. At the age of 100 years his remarkable memory remained intact. Well known political figure, Strom Thurmond, had the ability to serve in office as a US Senator representing the state of South Carolina even as he became a centenarian. In fact, in 1998, he received a special "Spirit of Hope" award for the longstanding service to his country. To this day his record stands as the longest serving and oldest Senator in US history, reaching 48 years of service at the age 100. Interestingly, we tend to place huge parameters around what is expected of people who enter the latter stages of their life. Increased health concerns, impaired vision, and loss of hearing are just some of our expectations. One wonders, when we hear examples of these Hollywood personalities and political office holders, if our expectations, regarding the aged, should be reversed.

But for our concern in this brief overview of dementia and Alzheimer's disease, we do need to consider the percentage of the population who ultimately experience gross impairment of memory and cognitive function due to the overall deterioration in the human brain. The important question we need to ask is "how does Alzheimer's disease *change* the normal human brain?" First we need to realize that, unlike normal "benign episodes" of forgetting, *routinely* forgetting items, conversations, and time and place, as well as experiencing impaired thinking abilities is *not* normal. Instead, such impairments

may be the signs of dementia. Most health practitioners consider the word "dementia" to be a rather generic term, covering a host of symptoms related to brain failure. Problems with concentration, the inability to handle some of the previously simple day to day routines in life, to managing personal finances, following directions, or even staying on track in a simple conversation may all be signs of clinical dementia. Furthermore, the roots of dementia may be varied and as the medical profession has discovered, Alzheimer's disease may be one of the leading causes of this.

It is true that we take a great deal about how we live our lives for granted. We give little thought, for example, to our ability to see, move about, breathe, feel, touch or form thought. Only until we are faced with some type of trauma do we look at these attributes more acutely. Our cerebral cortex (human brain) plays a key role in how we use these functions, and determines the parameters which allow us to lead normal, healthy lives. Essentially the human brain is, according to neurologists, a "high powered communications network. The average human brain has an estimated one hundred billion nerve cells, or neurons, that normally work in harmony through a series of intricate chemical signals to store, process, and retrieve information. There are an estimated 15,000 potential connections, or synapses, for each of these one hundred billion cells". [xii] With this in mind, we can easily conclude that normal brain function is acutely at risk if certain pathologies such as Alzheimer's disease and other forms of dementia disrupt this synaptic cell-to-cell communication. When this disruption occurs, we can almost always expect it to be accompanied by some form of life altering event or activity, or some significant changes in behavior, which will remove one from the normal realm of

function.

We may further wish to expand our original question by asking "Where did these *initial* questions and observations regarding age-related cognitive diminishment get raised?" It has believed that Alzheimer's disease has been around for centuries. Observations into peoples' behavior, particularly with reference to the acute changes noticed when the aged begin to show signs of cognitive decline, have been noted since the time of Plato. Nearly 2000 years ago, the philosopher himself remarked that someone who was "under the influence of old age", could not himself be responsible for his actions, and therefore should not suffer the consequences for any crimes that may have been committed. More recently, doctors began to offer medical explanations for abnormal behaviors they were seeing in their aging patients. Nearly 100 years ago a German Doctor by the name of Alois Alzheimer (after whom the disease was named) discovered, while performing a post mortem of one of his patients, several abnormalities within her brain. Her name was *Auguste D.*. In the latter part of the 19th century, Dr. Alzheimer began treating this woman who had been placed in an insane asylum in Frankfurt, Germany after family members began to notice increasingly bizarre behavior over a number of years. Early reports were that she became grossly confused in regards to her surroundings. She also had difficulty remembering where certain rooms of the house were located, and had forgotten, most of the names of simple household items.

By the time she was institutionalized, her deterioration had become severe. According to earlier writings of Dr. Alzheimer himself,. "On several occasions, during routine

hospital rounds, Auguste D. sent the doctor away with a string of curses, telling everyone in attendance that he was making sexual advances toward her... finally she became bedridden, forced by contractures to lie on her side like an infant, her legs drawn up and her arms curled across her chest". [xiii] In addition, much like the situation of my parishioner, "John", described in the initial chapter of this thesis, Auguste D. was showing the signs of displacement or *agnosia* (from the Greek text meaning "without knowledge") which is commonly associated with this disorder. Nothing within her world was recognizable. "The look and feel of certain objects no longer triggered any connection of what the object was, and what it is used for. Even though vision and touch remain relatively intact with the brain; what appeared to have been damaged is the ability to put these sensory inputs together into a concept of a recognizable object". [xiv]She had, for example, "a curious way of talking and would mix up words of similar or related meaning – she would say 'milk jug' instead of cup". [xv]Sadly, at the age of 55, Auguste D. succumbed to the disease which was later to be described and named through the careful and critical diagnostic work of her physician, Dr. Alzheimer himself.

Dr. Alzheimer thus felt it necessary to perform a post-mortem and brain analysis in order to gather insight with which to determine the basis for Ausguste D.'s plight, and to also make comparative notes regarding healthy brains during other post-mortems. If one was able to view a healthy brain alongside Auguste D.'s brain there should be measurable differences. A healthy brain allows a person to function normally in all of the aspects of day to day living, thus experiencing a variety of emotions and memories. Four small clusters of nerve cells within the *cerebral cortex* play a vital function in imagination and

memory. Neurologists are aware that the *hippocampus* is critical to the formation and consolidation of long term memory. The *thalamus* helps with simple day to day recognition of episodes and moments and is seen as an important relay station in the brain from the sensory organs to the cortex. Immediately below the thalamus is the cell structure named the *hypothalamus*, which plays a critical role in a person's ability to exhibit "normal" emotion. Finally, is that component of the inner brain structure known as the *amygdala* which governs emotions, stimulating our sense of fear, for example, whenever danger is present.

Individual's who suffer from Alzheimer's Disease have noted cerebral disturbances not found in healthy brains. 'Senile plaques and '*neurofibrillary tangles*' invade the small clusters of nerve cells in the Alzheimer's brain, resulting in interference with proper neuro-transmissions. When Dr. Alzheimer did his initial research on individuals with the disease, in particular the post mortem autopsy done on his patient Auguste D., he came to the conclusion that viscous looking *amyloid plaques* were evident, producing obvious neurological side-effects during the person's latter years. When he did detailed microscopic work, he noted atypical growths of what looked like "*splattered globs of paint*" across the cortex of the brain. "These plaques were so prominent that they could be recognised even on a cut section of the brain that had not been stained, as a large number of dense, irregularly edged black spots - very foreign looking, like microscopic craters in a biological battlefield."[xvi] These microscopic plaques became not only Dr. Alzheimer's chief discovery, but, a century later, they remain a prominent diagnostic tool in helping to diagnose the disorder in an individual. His findings then indicate that a

person who has this disorder becomes severely restricted in terms of normal brain function; which is needed to carry out every day tasks allowing them to engage in the world around them. Alzheimer's disease, according to today's American Health Assistance Foundation, "is defined as a progressive, irreversible brain disorder with no known cause or cure. It attacks and slowly steals the minds of its victims. Symptoms of the disease include memory loss, confusion, impaired judgement, personality changes, disorientation, and loss of language skills. Always, fatal, Alzheimer's disease is the most common form of irreversible dementia". [xvii]

Since the initial work of Dr. Alzheimer, our world has seen many advances in our coming towards a deeper understanding of this disease. Currently, the medical profession is looking at many diagnostic tools that no longer rely on the post mortem procedure so that an accurate picture of the brain can be viewed, and steps taken, to help the person while they are still alive. Recently developed diagnostic techniques, such as the Magnetic Resonance Imaging (MRI), and Positive Emission Topography (PET) Scanning, have allowed physicians to make images of the brain so that they may see where the disease is progressing. Ultimately, they are aiming to perfect a method of detecting Alzheimer's in its earlier stages.

Perhaps one of the major steps that has been made in the diagnostic evaluation of Alzheimer's disease is the recognition of the importance of gathering and comparing experiential information regarding the disease, from the patients themselves. Who better to offer insight than those who are experiencing the effects of Alzheimer's disease in their

own lives? On many occasions in my pastoral practice I have had people share that they *know* something is going on inside them that they have no control over. They are *aware* that there are times when they have full recognition of someone, and they are also aware that they have episodes where people that they *once knew*, now appear as strangers. With this in mind, it becomes apparent that one of the key aspects in making an accurate diagnoses is having an accurate historical picture of the person and making an assessment on the basis of the changes that are being noticed. In addition, the observations of spouses and other family members and friends can be crucial to help formulate the best medical opinion and diagnoses.

An additional important aspect to our understanding of Alzheimer's disease, particularly with regards to insights that may assist caregivers and persons who minister to them, are the progressive stages often found with the disease. Health experts, have documented common patterns which serve as useful reference points for how Alzheimer's disease might unfold in a person. The identification of these transition points now allow for more long range planning for the care of persons with Alzheimer's disease. Normally, within the average course of the disease, a person with Alzheimer's would experience seven stages of diminishment. It is also widely understood that a person affected with this disease does not necessarily progress from one stage to the next. There may be instances where they are exhibiting several characteristics of each phase, or they may 'by-pass' one phase and move into the next.

At the New York University School of Medicine's Silberstein's Aging and Dementia

Research Center, Dr. Barry Reisberg has developed several useful frames of reference for helping in the diagnostic process for Alzheimer's disease, as well as providing a better understanding of how the disease unfolds. According to his research, the initial stage of the disease shows very little impairment and there is little evidence during a medical interview of any noticeable loss of memory. As the individual enters the second phase the loss of certain memory patterns are slightly more noticeable, but these are still rare and transient. They may be seen in a similar light to the normative "benign forgetfulness" that nearly every person goes through. During the third phase, family members and close friends of the individual begin to notice that something is wrong. Here, word or name associations become problematic. In some cases during this phase, the actual detection of Alzheimer's disease can be ascertained.

By the time the individual reaches the fourth phase, according to Dr. Reisberg's frame of reference, there is a noticeable difference in how cognitive connections are being made and normal tasks such as arranging a meal or planning an event become increasingly difficult. The fifth stage offers even more impairment and loss and now there is strong evidence that the person is now loosing their perspective of time and place. Dates and names are extremely difficult to remember, for example. During this phase, there is also a greater decline in knowledge of their own personal history. Apparently, however, there is still some awareness of their own name, but the names of spouses and other people are no longer familiar.

In the sixth stage of progression, most of the day to day needs and personal hygiene

tasks are carried out by caregivers and family members. What is most noticeable here is a rapid change in emotion and temperament. It is not unheard of, during this sixth stage, to have frequent outbursts of anger as well as periods of hallucination. There have been cases where the individual, because of this advanced stage, starts to fear those who are closest to them simply because they don't remember or recognize them. If one is able to survive the progression of phases thus far, and reaches the seventh stage, profound losses of a spectrum of abilities are evident. There is a loss of bodily functions, loss of the ability to walk without assistance, the loss of the ability to sit up on their own, even the loss of the ability to speak or smile. They are totally reliant on caregivers and are most likely living in some form of institution.

The following chart may assist in clarifying the patterns of decline experienced by a person with Alzheimer's as they progress into the seven stages. As set out in the Aging and Dementia Research Center in the New York School of Medicine, the stages of Alzheimer's disease are:

Stage 1 - No Impairment (normal function)

Stage 2 - Very mild cognitive decline (may be normal age-related changes or earliest signs of Alzheimer's disease)

Stage 3 - Mild cognitive decline

Stage 4 - Moderate cognitive decline (mild or early-stage of Alzheimer's disease)

Stage 5 - Moderately severe cognitive decline (moderate or mid-stage Alzheimer's disease)

Stage 6 - Severe cognitive decline (moderately severe or mid-stage

Alzheimer's disease).

Stage 7 - Very severe cognitive decline (severe or late-stage

[xviii]

(The Aging and Dementia Research Center)

Upon reflection, there is no doubting that current diagnostic methods and stages, as a clinical frame of reference, are invaluable, providing the medical community and caregivers with a profound insight into this strange and mysterious world. This brief overview (albeit from a lay person's perspective) also suggests that we are still only scratching the surface when it comes to understanding parameters of this complicated disease. A more thorough investigation into some of its root causes, and a more detailed study of degenerative diseases of the central nervous system (which includes Alzheimer's and dementia) would be a mammoth undertaking and outside the intended scope of this paper. And yet, we are still drawn to ask questions. What do these clinical findings have to say about important theological issues around personhood, or concerning the church's ministry to persons suffering with this medical disorder?.

One of the theological concerns being raised at this point has to do with an understanding of the "self" or perhaps, more appropriately "the loss of self". If we were to reflect back on the insights provided by the recognized seven stages of Alzheimer's disease, one of the striking features of this disease is that Alzheimer's persons experience "profound losses" in a myriad ways. There are losses in the ability to remember names and places, there are losses with regards to personal identity and, certainly within the final stages of the disorder, there is a profound sense of loss in a person's ability to meet

simple, basic day to day personal needs. Perhaps the most graphic example of loss at this stage is the loss of control over their own bodily functions, the loss of the ability to walk on their own, or the ability to speak or smile. In essence, the *loss of self.* I am reminded of some of my encounters and experiences with my parishioner "John" with whom my initial journey into this world of the Alzheimer's afflicted began. (For that matter, some of the observations that Dr. Alzheimer used when he treated Auguste D. also apply.) As I reflect back on this, I am made aware how both individuals began to loose many powers and faculties. As their disease progressed, both John and Auguste D., began to experience a "slipping away" of the familiar. Neither of them, for example, were able to remember who they were. What became more and more evident, with the clinical onset of *agnosia,* was a marked decline in the number of "worlds" they were used to occupying. They became strangers living in a strange world. As they progressed through the various stages, more losses occurred; such as language, judgement, foresight and the ability to plan and hope for the future. Eventually, and this was certainly my observation of "John", there was a complete loss of self-awareness.

These tragic losses are also profound opportunities for further exploration in the theological realm of personhood. What, for example, constitutes the loss of "self"? Does the fact that one may have lost self - awareness, really mean that they have, in essence, lost "self"? My own observations lead me to believe that, in some profound way, the sense of "self" – even as it pertains to persons with advanced forms of dementia - *still exists*. Perhaps this deeply buried self was what was rising to the surface during my observations of my parishioner "John's" episodes of *awakening* during the Eucharist. As

he was receiving communion and hearing the words "The Body and Blood of our Lord and Savior Jesus Christ preserve your body and soul unto everlasting life", there was his repeated response of "Amen". For brief periods, while he was receiving the Eucharist, I also noticed John moving from a state of being almost catatonic to becoming more alert. What was going on? One might suggest that something profound, one might say 'divine', within "John" was connecting to a source beyond his limitations. In the midst of his advanced Alzheimer's stage it acted to remind him that his sense of "self" was *not* "lost". Even though "John" may have experienced losses or lapses in "self-awareness", we cannot make the conclusion that there was a loss of "self".

Where might this path be leading us in our search for a deeper meaning of what it means to be human; to occupy "personhood"? Time and time again, our attention is caught by the perpetual human struggle to find ways of expressing our 'essence' – 'our being' – in all stages of this pilgrimage called life. We find a sense of meaning, or a sense of "self" throughout most of this journey. It is only in the final stages, accompanied by loss, that our sense of "self" comes into jeopardy. This struggle is powerfully illustrated in Act II of William Shakespeare's play 'As You Like It', where the sense of 'self' is seen as whisping away to nothingness at the end of life's journey. Here, the character Jacques takes his listeners through the seven stages of the human journey that comprises life. The scene is set where "all the world is a stage", and as the years march along human beings are met on this stage with youthfulness, education, love and passion, maturity and service, and contentment. Finally, however, as the journey draws to a close, what was once youthful exuberance, full of goodness and vigor, is now void of the life it once knew. In

the end, it appears we are without anything.

"All the world's a stage,
And all the men and women are merely players:
They have their exits and their entrances;
And one man in his time plays many parts,
His acts being seven ages. At first the infant,
Mewling and puking in the nurse's arms.
And then a whining school-boy, with his satchel
And shining morning face, creeping like snail
Unwillingly to school. And then the lover,
Sighing like furnace, with a woeful ballad
Made to his mistress' eyebrow. Then a soldier,
Full of strange oaths and bearded like the pard,
Jealous in honour, sudden and quick in quarrel,
Seeking the bubble reputation
Even in the cannon's mouth. And then the justice,
In fair round belly with capon lined,
With eyes severe and beard of formal cut,
Full of wise saws and modern instances;
And so he plays his part. The sixth age shifts
Into the lean and slipper'd pantaloon,
With spectacles on nose and pouch on side,
His youthful hose, well saved, a world too wide
For his shrunk shrank; and his big manly voice,
Turning again toward childish treble pipes
And whistles in his sound. Last scene of all,
That ends this strange eventful history,
Is second childishness and mere oblivion,
Sans teeth, sans eyes, sans taste, sans everything".

[xix]

(William Shakespeare)

It would seem that the poignant phrase that is voiced by Shakespeare's character, Jacque, is that of *sans or without*. Is it really true that without our eyes, without the ability to have sight, without the ability to have taste, or in the journey of those within the Alzheimer world - without the ability to remember or process thoughts normally, that we

are actually "without self"? From a diagnostic point of view, there are a number of scientific observations which certainly cause us to be aware of the profound 'losses' experienced by the Alzheimer person. Yet it would also seem that there is a more hopeful way to approach things. There is little debate in suggesting that diagnoses provide structures which enable physicians to, hopefully, move patients from a state of disease to a state of health, or to at least to alleviate their suffering in some meaningful way. John Swinton, in an article written for the Journal of Religion, Disability and Health, reminds us that as important as the diagnostic process might be "they do not (or at least should not) comprehensively define the nature of the experience of the diseased person. They can tell us *some* things about dementia, but they cannot tell us other things. One of the errors that has been made in seeking to understand people experiencing Alzheimer's disease and other forms of dementia is that we have allowed the diagnoses and the diagnostic characteristics to determine the way in which we conceptualize and act towards the person who receives them". [xx]

These comments are extremely helpful. They make room for the theological perspective which says our "personhood", and sense of "self" finds it origins in the deliberate actions of our Triune God, who connects with us and responds to us throughout this life and beyond. In light of this what gifts can the Christian church offer so that, in concert with the medical community, 'recovery of the self' for the Alzheimer person becomes a universal concern. According to our earlier reflections from the writings of St. Augustine of Hippo, the church community must strive to instil hope in the lives of people even though they may be on the widest possible fringe, to draw them into a deeper

experience of the love of God, and to remind them of their sense of "self" through that love.

We also see evidence of this type of pastoral support from medical community itself. Returning to some of the earlier work done by Dr. Oliver Sacks, whose insight has been influential in my own theological enquiry, we are reminded that the sense of self is not necessarily lost whenever there is any acute abnormality within the human condition. In his own observations as a clinical neurologist, he sites examples of many of his patients who have the miraculous ability to retain parts of themselves, musical ability, for example, even though they have entered the final stages of Alzheimer's disease. In his book Musicophilia, Dr. Sacks tells of one gentleman, whose wife was under his care, noted that although his wife had been diagnosed with Alzheimer's disease seven years ago – the essential person miraculously remains..."she plays the piano several hours daily, very well. Her present ambition is to memorize the Schumann A-minor Piano Concerto... Yet, according to Dr. Sacks, this is a woman who is, in most spheres, grossly forgetful and disabled. And what is most striking here is not merely the preservation but the apparent heightening of musical powers and sensitivity, as other powers wane. Rather, the extremes of musical accomplishment and illness are so plainly evident in her case; a visit becomes miraculous as she transcends the disease with music". [xxi]

These observations by Dr. Sacks carry within them a sense of hope not unfamiliar to the Christian church. Even in the dark depths of dementia, light can shine and miracles blossom. It is as if identity has such a deep and profound basis – God rooted, and

ingrained within the human psyche – that it is never wholly lost. When we consider our own ways of connecting with those who have this disease – the sacramental offerings, the Biblical story, hymns, and rituals – the Church can do no other but continue to remain open to the miracle of the presence of "self", regardless of the impairment wrought by Alzheimer's disease.

Glossary of Terms Associated with this Chapter

Agnosia – Loss of the ability to identify everyday objects and their uses.

Amygdala – A mass of grey matter in the anterior portion of the temporal lobe.

Amyloid plaques – A protein complex having starch-like characteristics produced and deposited in tissues during certain pathological states.

Cerebral cortex – A thin layer of gray matter made up of neuron dendrites and cell bodies that compose the surface of the cerebrum.

Hippocampus – The hippocampus is a part of the forebrain, located in the medial temporal lobe. It is responsible for short term memory, and damaged early in Alzheimer's disease.

Hypothalamus – A portion of the floor lateral wall of the third ventricle of the brain.

Neurofibrillary tangles – Groups of threadlike fibers found in brain cells damaged by Alzheimer's disease.

Thalamus – Located just above the hypothalamus; its functions are to help produce sensations, associate sensations with emotions and plays a part in the arousal mechanism.

Chapter Three

As we continue in our theological enquiry into a deeper understanding of personhood and the Alzheimer's individual, we must acknowledge the restricting influence and pervasive practice of ageism. At every stage in our lives we are met by the inevitability of our own ageing. As we journey through life, we cannot help but be reminded of the affects of ageing as it relates to the relationships we engage in, the physical changes we notice within our bodies, and the attitudes we accumulate that help shape our surroundings. Generally speaking, we tend to create close relationships with people who are the same ages as ourselves and, whether or not we believe it, most of our day to day decisions are aged-based, including social judgements. Naturally, there are exceptions to this rule, and we do find moments and relationships in which our awareness is raised as a result of age diversity. We tend to hear, for example, about Hollywood personalities who have married or entered into relationships with people a fraction of their age. John Macnicol, in his book, Age Discrimination, An Historical and Contemporary Analysis, reminds us of a powerful example of this in the life of the actress Joan Collins. "In 2002, the actress marred a man thirty-three years her junior, and it was newsworthy, not merely as a tabloid story, but because it broke such unwritten and powerful rules about aged – based relationships". [xxii]

Society is still attempting to gain a deeper understanding of how we look at life on the basis of age. The underlying feeling, however, is that age is still a powerful trigger of discrimination in our modern world along with class distinction, race, ability, gender, and

orientation. Here, people are not only open to powerful, and sometimes overtly violent episodes of discrimination, but they often find themselves deprived of some of the most common expectations of life, such as equality in the work force, a voice in society, or political freedom. Hence, they are seen as a people with little influence or power. Noted psychologist A. J. Traxler defines ageism as, "any attitude, action, or institutional structure, which subordinates a person or group because of age or any assignment of roles in society purely on the basis of age". [xxiii]This is yet one more burden to be borne by those struggling with Alzheimer's disease.

A.J. Traxler's insights clarify the potential depth and breadth of how people, simply as a result of their age, might be treated. We must be mindful that not all situations of ageism are blatant. People are often brought to submission through very subtle methods which still result in fewer opportunities to experience full and free lives. In this third chapter we are led to consider the following questions, "How does ageism and its quiet subtleties manifest its way into the life of faith communities, and what are the social implications arising as a result of this?" One way of entering into this discussion is to look at some of the perspectives regarding the sense of value placed on human life as outlined for us in the scriptures. At the very heart of the Christian Gospel, for example, we find a very curious message given by Jesus to his disciples which has generated much discussion and reflection over the years. In the Gospel according to John, we hear Jesus saying the following words:

> *"So again Jesus said to them, 'Very truly, I tell you, I am the gate for the sheep. All who came before me are thieves and bandits; but the sheep did not listen to them. I am the gate. Whoever enters*

by me will be saved, and will come in and go out and find pasture. The thief comes only to steal and kill and destroy. I came that they might have life, and have it abundantly'." (St. John 10:7-10) NRSV

What might Jesus have meant when he said this? Since its inception, it has been our common understanding that much of the church's mission; through her teaching, pastoral care, and evangelism - has defined the core of the human experience to be the God-given mandate to have life, and have it abundantly. This is particularly evident within current context in which congregations engage in ministries specifically to explore this question so that they might assist and empower people to becoming fully alive persons, living to their fullest potential. We see this, for example, in the wide range of outreach programs designated for youth on the fringe; ministry to the poor, food banks, drop-in centres, support networks for single parents, and the like. The same can be said, of course, for its mission towards those others who are on the other end of the age spectrum of society, namely those who are elderly and the infirm. One might therefore draw, from this Gospel text, the conclusion that fullness of life is something toward which we are constantly moving. It is a life process. After all, the community of faith is comprised of persons on a journey, en-route to completeness and wholeness through growth, through change, through searching and through development. If what our tradition and the Gospel tells us is true, life is a continual process of growth, of movement and of development. Life, then, can be seen as a constant challenge to accept this reality as expressed by Fournier and O'Malley in their book, Age and Grace. "This outlook demands growth and change at every stage of our lives right up to and including our death, which, the noted psychologist Elizabeth Kubler-Ross calls 'The Final Stage of growth'. To deny the

possibility - the necessity - of growth even in old age, for ourselves or for others, is to give up on life prematurely, to loose our sense of life's direction, and to settle far less than the fullness of life of which the Christian Gospel promised". [xxiv]

One of the great myths, however, as pointed out earlier, is that this mandate to 'abundant life' for the elderly is being fully attended to in both general society and in faith communities. Research and experience tell us otherwise. Instead of affirming the ageing process and all of its attributes society, and particularly individuals in positions of power end up trying to deny the signs of ageing in us. We live as if life only has meaning and value when we are young. If one is fortunate, for example, to be a young, single, heterosexual, employed, white-male then, and only then, are they considered as having full and significant value as a person. The reverse is seen in terms of the elderly. Rather than being perceived as being free and able to experience the wonderment of life, the aged fall prey to myriad stereotypes in which they are labelled as being senile, or rigid in their beliefs and convictions, and certainly non-adaptable to change. Furthermore, once one has lost the attributes of youth and has transitioned to the less attractive responsibilities of middle adulthood, eventual maturity holds few expectations other than death. We hear this explicitly in one of the most revered poems by John Keats, "*Ode on a Grecian Urn*", in which the youthful figures displayed on the urn are celebrated because they will never succumb to the fate of growing old or perishing. Ironically, according to one writer on the subject of ageism, "Keats never had to cope with these problems of ageing because he died at the ripe old age of 26, having met that one inevitable fear with which is linked all too soon". [xxv]

"Fair youth, beneath the trees, thou canst not leave
Thy song, nor ever can those trees be bare;
Bold lover, never, never can thou kiss,...
She cannot fade, though thou hast not thy bliss,
For ever will thou love, and she be fair...
When old age shall this generation waste,
thou shalt remain, in the midst of other woe
Than ours, a friend to man". [xxvi]

(John Keets, 1820)

If our enquiry is to be an honest and serious attempt to understand the oppressive forces behind ageism, it is necessary to examine them through a theological 'lens' perspective which reinforces the well being of all people. What might one look like? Such a perspective requires that we see God as the hater of anything remotely close to life-denying and health destroying and, instead, as a lover of life-affirming and health promoting change. Donald Chinula, in his ground-breaking work in unpacking the profound teaching of Dr. Martin Luther King Jr's pastoral approach, suggests that a theological perspective that both embraces and affirms the transforming nature of God is vital to the health of any Christian community. Without it, they will die, or worse, they will work against the tide of the intent of Jesus' Gospel. His entire precept is based on the idea that God loves life. "In so doing, God affirms health, and promotes biophilic and salugenic (health-giving) communities. God will not sit impassionately in the face of death-dealing status quo. Emotional, psychological, and spiritual death is equally displeasing to God. In the face of these diabolic forces, God becomes not changeless but a *change agent* for the good and for health". [xxvii]

Historically, however, acceptance of God as "a change agent for good and for health"

is shown to be a process fraught with tension. Many well-intentioned groups and individuals, through their rather bizarre understanding of the nature of God, have reinforced negative patterns as they pertain to human value. Some of the results of this way of thinking have been outright oppressive. To site one example of this, Donald Chinula goes on to describe how certain Biblical narratives have been used to promote intolerance and to retain power over individuals who have little or no voice. The Genesis story of Noah and his descendants, particularly in regards to his son Ham, is a case in point. As told in the story Ham, father of Canaan, commits an indiscretion concerning his father's sexuality. Ham sees Noah naked and apparently treats his intoxicated and slumbering father as an object of humour. When Noah awakes, he is told about Ham's behaviour. Because of this act of disrespect Noah ends up blessing his other two sons Japheth and Shem, with lives of prosperity while cursing Ham and his offspring. Further on in the Genesis story the influence of this curse extends to the point that "all the descendants of Ham are named, and the list includes Canaan, Cush, Put, and Egypt. Thus, to some misinterpretations and strange exegetical logic, the Hamite theory ends up identifying Ham and his descendants as black people who were biblically cursed to serve the white descendants of Shem and Japheth. In so doing, some biblicists have taken this passage to its extreme in order to justify the enslavement and oppression of blacks".[xxviii]

In a similar manner, other biblical passages have been used to indicate divine approval of situations that are both oppressive and life debasing. History reveals that during the establishment of the North American colonies, it was common to interpret St. Paul's instructions to the early Christians supporting the economically profitable slave trade

while at the same time reminding those in submissive positions that this was the fulfilment of the will of the 'master on high'. After all, it was supported by Scripture in the letter to the Colossians:

> *"Slaves, obey your earthly masters in everything, not only while being watched and in order to please them, but wholeheartedly, fearing the Lord. Whatever your task, put yourselves into it, as done for the Lord and not for your masters, since you know that from the Lord you will receive the inheritance of your reward; you serve the Lord Christ. For the wrongdoer will be paid back for whatever wrong has been done, and there is no partiality".*
>
> *(Colossians 3:22-25 NRSV)*

This being the case, it is not hard to see how the same oppressive, albeit subtle, components can be found in the 'good works' of youth communities as the attempt to meet the perceived needs of the marginalized, including the elderly. Modern and well-intentioned theologians have continued to reinforce old theological models which focus solely on the negative aspects to the ageing process. They base their ministry models approach on early Augustinian understandings wherein he is said to have described old age as a manner of an inferior age, lacking in lustre, weak and more subject to disease – namely, it leads to death. Professor Fredrica Harris Thompsett in her book entitled Courageous Incarnation takes issue with this perspective, saying that "when such theological approaches are used - which stereotype aspects in the life cycle - then *theological ageism* is given birth to. When this happens, there is an unexamined presupposition that ageing is inevitably marked by a series of losses without moments of life or growth". [xxix]

At this point it would be helpful to ask ourselves, "What does ageism *look like* in the average parish context? How does it directly affect the elderly, or even those who have entered into the world of Alzheimer's disease and dementia?" The theological work of Homan and Pratt offers valuable guidance as we attempt to answer these questions. In much of their work regarding the practices of Benedictine Spirituality, they remind the church that, in order to fully live out the Gospel intention of life for all people, it must be intentionally radical in its dismantling of all forces that work against the Gospel directive. In their book Radical Hospitality: Benedict's Way of Love, they introduce us to the concept known as 'The Other'. Here, they define "The Other", in the Christian context by basing it against those who hold positions of authority or defining roles in the life of a given parish. In any normal church setting, there are always groups and individuals who have a certain amount of political power which often influences how decisions are made and directions taken. It may be a specific governing body within a congregation, such as elders or wardens. It may even be families who have had a lengthy association with a particular church who believe themselves to hold a prominent position. According to Homan and Pratt, "The Others are the ones who you have the power to systematically marginalize and / or oppress. They are, to borrow from the Visions Group (a congregational development organization which teaches anti-racism), the targets of oppression, while those who hold privilege and power are non-targets". [xxx]

Upon first glance the tone these authors use appears quite harsh. They are not saying, however, that there is necessarily any overt intention to dominate one particular group or individual, although this may occasionally happen. Rather, Homan and Pratt are

reminding us that to identify 'The Other', requires only "the recognition that, within the social system in which we all function, some groups have been given social, economic and political power over other groups".[xxxi] Simply put, it is the potential to exercise *power over* one group or another that works against the health and wholeness of a Christian community which would otherwise operate in a manner that welcomes, accepts and embraces all. The constant struggle in the Christian context is to continue to see "The Other" as individuals with their own unique stories and perspectives who have a great deal to offer in the life of the community.

What might the Other look like? Let us look at a specific case study from my own ministerial practice. Unlike "John's" situation, where most of my observations were done at the care facility in which he was living, "Jane" (not her real name) is still an active member of my present parish. She has been the organist in this church for most of her life. Jane is now in her early eighties and is beginning to show the normal signs of frailty for a person of her age and stature. On several occasions, she has shared with me that she feels somewhat frustrated regarding the challenges and transitions that she is now facing. She has expressed a tension regarding potentially having to step down from the position, while still having a keen desire to play whenever she is able. Music, in addition to the social network of the parish family, has been her life. On one occasion I was honored to hear her speak candidly about how passionately she feels regarding her music. She shared with me that when she plays, she can feel God's *pleasure* - she feels *alive* inside.

After hearing some of her life's story, I can understand why this is so. In her

earlier years on the Canadian prairies, she worked at a music teacher to young children, often teaching out of her home. As her life progressed, her musical gifts took her to the performance level, allowing her to not only play in public, but to also get exposure and experience necessary to offer her gifts to the church. Later, she would become the lead musician and has remained as such so for the past several years. One interesting note in Jane's journey is that even though she is in her early eighties now showing a variety of the signs that accompany the ageing process, Jane has not lost her gift of music nor her passion for playing. In fact, her talents are still being channelled in other ways beyond the parish setting. Although the years have admittedly taken their toll on her musical ability, she regularly offers her gifts by playing the piano at two of our local care-home facilities.

Jane's story, I believe, offers opportunity for personal reflection. As I think about her situation, I realise that it is a common challenge in most parishes to be faced with the age related concerns of individuals who have held honourable positions for several years, if not decades. At one level, Jane's situation could easily be seen as an example of some of the day to day struggles within any parish particularly in light of most church communities resistance to change. A closer observation, however, offers another interpretation. Interestingly, throughout this entire process, there has been a litany of congregational responses focused on the *age* of Jane, and her struggle to adapt to changes in direction as the parish evolves. Many of the elected parish officials, for example, have entered the discussion and have directly stated that "*she should step-down"* in order to allow for new growth to occur". These comments are often followed by further age-based assumptions regarding her physiological condition. "*Naturally, Jane is showing signs of*

deterioration... she is more confused. She is, after all in her late 70's... It seems as if she may even be starting to have dementia...". Curiously, as these statements have been put forward, there has been little evidence from the family that she has any diagnostic signs of any disorder.

This scenario reminds us of the important work of Homan and Pratt introduced earlier in our discussion. A power group, in the form of parish officials, is at work here. They are operating within the social system of the parish to make change at the expense of someone. In other words, they are practising discrimination regarding Jane's value to the parish based on her age. The stereotypical assumptions that would naturally follow as a result of this claim of age related diminishment suggest that Jane has now entered that stage in her life where she can *only expect* to have episodes of confusion and possible memory loss. Because of these assumptions she has been placed in a specific category wherein the focal point is a series of losses. It is implied that Jane can no longer function in the same manner as she once could, so this should be a deciding factor in having her step down. Furthermore, there is the loss of status, because those in positions of power, have now placed her identity at risk by suggesting that she no longer do that which she has previously always done.

I believe that Jane's scenario is not unique when placed alongside our discussion around ageism. Within any social network, whether it happens to be a faith community or otherwise, there is always the potential to push forward ones' own agenda and wield power over a group that falls into a specific subcategory based on age, orientation, class

or race. Also at work here is in the use of language statements that *place* people into categories, further putting them at risk for additional oppression and discrimination. Jane's case study brings us closer to a deeper understanding of how 'language – statements', particularly when focused on our identity can, in fact, shape our sense of our own reality. This experience mirrors the powerful reflections of Paulo Freire who, in his treatise on Pedagogy of the Oppressed, argues very strongly regarding the *power* that language has. From his own experience of working with Latin American communities, Freire describes how those in power continually retain the upper hand by making 'statements of identity' towards those perceived as powerless. The mass population in Cape Verde, South America, using one of his examples, has a majority of people living in situations of abject poverty, this was seen as the normal way of life. This is how it is. "*The poor, we always have with us*"; this scriptural passage from the Gospel of John is widely used in situations such as these and, as such, is widely taken out of context. From the perspective of the powerful statement 'they are *always* with us' has to mean that poverty is a life long condition immune from any change that they might consider initiating. Solutions, in the eyes of the solvent, are impossible; any attempt to prove otherwise is not only futile, it refutes scripture.

The same argument can be made about others who are made powerless in Christian communities, where 'statements of identity' are used as a precursor to the determination that *this is how it is*, so therefore nothing needs to be done to change or alter the situation. Older persons, like Jane are under the operative norm which says they must inhabit the category of having less to offer, now that they are in their "dotage". They must also

accept that because they may be experiencing age related physical transformations which could result in memory and hearing loss, visual impairments and other 'limitations', it is predetermined that there will soon be nothing of value left for them to offer. As language is such a formative tool to our understanding of self, it is easy to see how a person's sense of identity is threatened when such dismissive statements are in use. Our very humanity is at risk. Oppressive language, *steals* our humanity, replacing it with dehumanisation. As Freire was to discover in his work with the underprivileged, a key element at work in this theft of humanity is the distortion of the expectations of the oppressed. Because of this, full personhood is no longer seen as an option. The sad reality is that this has now been ingrained in the Latin American culture has become, as he observed, rooted in its history. In order to change the situation, there had to be the recognition of a potential alternate reality and an intentional movement towards emancipation in order that 'humanity' might be regained. He claimed that "the struggle for humanization, for the emancipation of labour, for the overcoming of alienation, for the affirmation of men and women as persons would be meaningless. This struggle is possible only because dehumanisation, although a concrete historical fact, is *not* a given destiny but the result of an unjust order that engenders violence in the oppressors, which in turn dehumanises the oppressed". [xxxii]

If we are prepared to take Friere's work to heart then we must also be prepared to regularly review all of the structures in place within the various communities in which we live and operate. In Jane's case study, we are met with one form of ageism. In this light we need to offer new perspectives that raise people such as Jane away from statements of identity based on age and towards theological perspectives that offer affirmation and

promise. To move forward in our discussion it is important for us to explore forms of ageism which are not so obvious. Insidious ageism, we might say, is a way of inflicting oppression from a 'safe distance'. The source of this subtle form of ageism is often difficult to detect. To begin with, there are no hate groups in our present society that explicitly target the elderly as there are hate groups that target members of religious or ethnic groups, for example. Elder abuse is a crime; a threat to body and soul. Subtler forms of oppression, while not always seen as criminal acts, can also be life altering. When one's influence and authority is *taken* because of age, an assault of sorts has occurred. People can be subject to a plethora of losses, whether it be status, value, or employment opportunities all because they have reached their 'golden' years. Jane's situation may be a form of this, because her oppression has come via 'language statements' that have now shaped her present reality. "Jane is now just too old, and because she is this age, she should step down".

Ageism is not always intentional. Without adequate thought, well meant attitudes and actions can, nevertheless, end up being diminishing and oppressive. To explore what this might look like, we turn now to our second case study, and offer important reflection on "Margaret's" situation. Margaret (not her real name) is a lady who has served as a faithful member of our parish Altar Guild. She is in her late seventies. Until recently, Margaret enjoyed relatively good health. Several months ago, however, her situation began to change. Her husband started noticing patterns of behavior that were 'out of the ordinary'. She had started to misplace objects around the home, common household items not easy to loose. At one point she complained of not knowing where the frying pan was, and after

several attempts of asking her husband for assistance, it was discovered that it was within arms reach all of the time. Other household items also went missing, such as a baking tray that ended up being found in a closet where clothes were normally kept. After time it became clear that Margaret was loosing a sense of time and space, as she began to have episodes of not knowing the function and purpose of very common items in the home. She could, for example recognize that an object was "frying pan" or a "tea-cup" but she had no idea what these items were used for. When her husband finally took her to their family doctor, it was determined that she was entering the early stages of Alzheimer's Disease.

When I have made regular pastoral visits with Margaret I have been pleasantly surprised by her candidness and her willingness to talk about her condition. On several occasions she has remarked that it is helpful for her to talk about how her life is, but that she also knows that something is going on inside of her that she has no control over. When I hear comments like this, I realize what a profound effect her journey into the world of Alzheimer's Disease is having on her life and how there must be a deep struggle on her part to maintain a sense of belonging in the church.

Normally the parish's Altar Guild meets weekly, and because this appears to be a very close knit community, there is the sense that church is an important part of the lives of many people who are around Margaret's age. Recently, however, it has become obvious that Margaret is experiencing a greater struggle in terms of her sense of identity and belonging within the Altar Guild group. Now that she is facing Alzheimer's Disease,

she has become more aware of her limitations and has quietly made the decision to withdrawing from some of her normal activities in church life. She has become quite anxious, for example, about crowds and this seems to have affected her desire to venture out in public. On several occasions she has indicated a fear of making mistakes when it comes to setting up the altar and sanctuary area for Sunday worship. She is concerned of what people might think if they witnessed her forgetting something or making a mistake. Even though the parish Altar Guild has a policy in place where the members work in "teams" when preparing the sanctuary for worship, this fear has led Margaret to make an almost complete withdrawal from any involvement, and in the last couple of months, she has only been in church a few times.

To add to Margaret's struggle there appears to be a further sense that, because of her condition, her ability to make decisions on her own is becoming more limited. Although she is still in the early stages of Alzheimer's Disease, and she is still able to function reasonably well, there is still very little Margaret can do on her own. Her independence has waned to simple day to day decision making, whereas any important issues are now in the hands of either family members or close friends. The world Margaret once knew, with its freedom and choices, is becoming smaller and smaller. As one reflects on her new world, and on the earlier comments made by both Homan and Pratt, one wonders if Margaret has now been placed among the so-called "Others" in our society.

Margaret's struggle with her sense of identity, offers additional opportunity for reflection on inclusion of 'The Other" in established faith based communities. As one

might imagine, many persons within the parish are struggling to come to terms with Margaret's new health situation. How, for example, do they treat her now that it has become common knowledge that she has been diagnosed with Alzheimer's Disease? How is her membership in the Altar Guild now seen in light of her new condition? As these questions are put forward, it is interesting to see how some of the Altar Guild members are attempting to come to terms with Margaret's place in their midst. As one example, at a recent meeting of the Guild, there was a lively discussion around the overall health of Guild members, recognizing the fact that most of the ladies were now into their mid 70's and early 80's. Margaret's situation was also discussed, even though she herself was not present at the meeting. During this time there were some serious concerns expressed that Margaret might be experiencing greater difficulty in trying to accomplish some of the usual duties of the Altar Guild. Normally their work involves setting up various candles and vessels on the Altar, in a specific order. In *an attempt to be inclusive*, and not meaning any offence, one lady made a very interesting motion. She suggested that because Margaret could no longer execute certain tasks expected of a Guild member, Margaret be declared "an *honorary* life-time member". It was evident that this would be a *non-active* role. A vote was taken, and Margaret was unanimously "lifted" to this new *special* membership status. As the meeting ended, the comment was made that finally we have addressed this situation and we could now move forward knowing that Margaret's needs, in light of her new life's situation, have been met.

At first glance, this whole process appears to be an admirable gesture, recognizing someone who has served so faithfully over the years and acknowledging Margaret for all

her past contributions. Unknowingly, however, they also burdened Margaret with an additional sense of loss. As I have mentioned earlier, one of gifts that Margaret brings to the life of our parish family is her honesty and her candid attitude regarding her journey into the world of a Alzheimer's Disease. There is the sense that this newly bestowed title may place her into yet another area of abandonment. How, for example, does she both face and adjust to this new designation? Does it imply that because of her condition, Margaret is now a member of the parish Altar Guild in *title only* and will rarely, if ever, be asked to be involved in some of the day to day routines of the guild?

I believe the discussion regarding Margaret's situation, as it evolved that day at our parish Altar Guild meeting, is a profound reminder of how challenging it is for individuals and communities to make sense of, and appropriately respond to, life-altering events. In this particular set of circumstances we are observing a deep struggle to come to terms with a physical and cognitive condition for many that is deeply mysterious and incredibly difficult to understand. This dilemma is discussed in the work of physicians, Dr. William Molloy and Paul Caldwell, who suggest that the world of the Alzheimer person is so blurred that its very mystery is equivalent to an unwelcome guest. "Day after day the person they once knew changes, often in bizarre ways, until one day only faint traces of the former person remain. Their husband or father, their wife or daughter, along with close friends, has been replaced by a bewildered stranger". [xxxiii] In Margaret's situation, offering her the title of "honorary life member" may be the Guild's only attempt to describe an uncontrollable event happening to someone for whom they have a great deal of admiration and affection. It may signify that they are at a loss as to what to do.

How true it is, as this scenario suggests, that within humanity's own struggle to understand complex issues, our initial reaction is to allow our fear of the issue to "remove it" for comfort's sake.

The circumstances of Margaret's situation is also a reminder of how subtle forms of ageism, though often unintentional, can further alienate people, excluding them from fully participating in life and all its gifts. The key word in this case study is its *subtly*, for it's clear this was not an intentional act to take away Margaret's voice or remove her from the community. It is a case of very concerned, faithful members attempting to provide a level of care for someone whom they have known for many years and who is now journeying through a landscape that is foreign to them. In essence, what is happening is a prime example of the ongoing struggle to place our theological perspectives alongside the very real need to find creative ways of keeping "The Other", as Margaret has become; in community with her peers. Raising Margaret to the isolated position of honorary life-time member has brought that creative force to a halt. There is nothing left in this honorary role to remind her of her place, as *an active* member. Again we are reminded of earlier reflections of Homan and Pratt regarding the need for all systems, particularly those within the Christian community, to explore all ways possible of becoming welcoming and inclusive.

As well as casting a revealing light on the pitfalls of more specific forms of ageism, both Jane and Margaret's stories also lead us back to our initial search for a deeper understanding of personhood. This examination of the world of ageism reminds us that

while, regrettably, faith communities have elements within them which have the potential to be destructive, there are also positive elements that invite us to journey forward and to reconnect with theological frameworks and languages that are live giving. The call here is for every community to be authentic, so that, as a body, they manifest the Christian message and strive to embrace all people in their journeys – regardless of orientation, gender, race, ability or age. By attempting to live in a community of people who are all struggling with their sense of identity and belonging, we will be brought into the very purposes of God. Both Jane and Margaret challenges us to answer this call. Margaret, having now entered the strange and complex world of Alzheimer's disease, and Jane, experiencing the stereotypical results that accompany aging which can only lead to physiological deterioration and memory loss, have become "Others". Yet, to merely define them as "Other", and, even worse, to leave then as "Other" will only serve to further alienate them from the very community whose vocation it is to offering life and wholeness to all its members.

Homan and Pratt's views regarding the need to create holistic communities are echoed throughout the theological - academic world. Miroslav Volf and Dorothy C. Bass, authors of the book Practicing Theology: Beliefs and Practices in Christian Life, offer a paralleled insight suggesting that faith communities must integrate their beliefs with their actions. In other words, they must 'practice what they preach'. People of faith must not only be willing to discern what resources held within the community are the most helpful, but they must take the next step in the journey by also discerning whether or not what they are doing is in connection with the purposes of God. According to Volf and Bass, "each

community of Christians in every generation is already engaged, implicitly or explicitly, in just such discernment. Inheriting much but also drawn into relationship with God in Christ in the present moment, they care for the sick, bury the dead, bring up children, tell stories, and make decisions, sometimes pausing in midstream to discern the possible intention of the Spirit".[xxxiv] One would hope that *all* Christian communities are involved in a constant search for truth and meaning. One would also hope that, those within these communities strive to live out their lives under the guiding influence of the Gospel stories and the ways of Jesus.

The question here is, how do we help to bring all of the Janes and all of the Margarets into communities which are constantly weaving their beliefs and practices together in order that they might fulfill the mission of God? Are there ways, in Margaret's case, for example, of making her feel more connected and helping her regain her sense of identity and purpose, while, a the same time, seeing herself as one who truly *belongs*? In Jane's case we might raise questions about language – statements that affirm her as a person of value and worth, instead of stereotypical age related comments which focus on loss and limitations. Asking parish communities to judge whether or not they are making honest attempts to remain faithful to God's purpose is an unenviable task. It may provoke negative reactions. It could lead to criticism. Yet, to encourage this kind of theological reflection is also to claim our role as people of the Triune God and to become instruments of redemption. Participation in the work of God puts into place opportunities for nurturing and for growth. The task may seem like a struggle against a strong current, but it is one which has the ability to offer a ripple effect of promise on a universal scale. In the

following chapters we will explore how this discernment process is 'fleshed out' within faith communities. We will also see how the gifts of the church – Eucharist, rituals, hymns, the Biblical story – help to mold a model that not only supports the value and dignity of all people, but further dismantles the foundations of ageism.

Chapter Four

As we continue our journey towards an understanding of personhood as it relates to those struggling with Alzheimer's disease and other forms of dementia, we focus now on the need to create an effective model providing pastoral care. This journey has been walked, in part, alongside colleagues in ministry. Their insights will prove able tools to assist with the task at hand. Previously I made mention of some of the special gifts of the church – ritual, the Eucharist, the biblical story, hymns and prayer –gifts which have allowed me to make deeper spiritual connections with those to whom I minister. The story of the effects of receiving communion on my parishioner "John" provides an example of this. You will recall that he also showed signs of an *awakening* when he was offered prayer. These insights and observations will contribute to taking our enquiry to a new and deeper level. Not only will we be looking at ways in which the *specific* gifts of the church can help minister to persons with Alzheimer's disease, but also how they can become the means of regaining personhood – thereby claiming solidarity, and the ability to effect change in, the society that previously shunned them.

One of the ways in which information and insight has been gathered during this process has been via the distribution of a survey questionnaire. In the fall of 2006, 72 questionnaires were sent out to active clergy of the Anglican Diocese of British Columbia to ask about their practices and experiences when offering pastoral care in Care Homes. The questionnaire contained seven specific areas of enquiry: the present ministerial context; the forms of ministry offered, such as hymn sing or Holy Eucharist; the content

of the worship (choice of hymns and readings); the practice of the clergy themselves (the use of vestments and other signs of ministry); the connections with the residents in the care homes (How did they respond during the service? What did they offer?); specific ministry to persons who have Alzheimer's disease and other forms of dementia; and finally, the level of comfort of the clergy themselves in providing effective care.

Within one month of the questionnaires being distributed, 40% were return completed, while one was returned unanswered for reasons unknown. It should be noted that, due to an error in numbering, there was no question 27. None of those who responded chose to answer question 12. I surmise that the reason for this was that the question itself seemed irrelevant. Question 12 asked "on what occasion would clergy wear vestments?", while question 11 asked "when you offer pastoral ministry in Care Home Facilities, do you wear vestments?". Many of the answers to the survey questions were detailed, and there was the sense that a good number of my colleagues felt that this was an important survey to complete and that they were happy to do so. There were even some unsolicited notes, included with completed questionnaires, encouragement to me to continue in this work – an area of ministry that has very much become my passion.

Reflecting on the responses to this survey questionnaire, I am drawn to make certain observations and conclusions. It appears that *familiarity*, whether having to do with the selection of hymns or scriptural verses, plays a large part in the positive outcome of a service. Nearly, 100 % of the responses to questions regarding service content noted that with the choice of familiar hymns, whether "Jesus Loves Me" or "Tell Me the Old, Old

Story" and well-known passages of scripture, such as the 23rd Psalm, the service and its worship tended towards a more natural and rhythmic flow. This suggests that not only are emotions triggered when something recognizable is sung or heard, but more people will engage in an event when a familiar dynamic is introduced. Those who answered the question regarding hymn selection observed that, although there is a preference on the part of some clergy to use other resources (different hymns or songs of praise), the *choice* of many residents is to hear hymns that are 'simple', traditional, and ones which have been sung over and over again. Here most clergy use as a resource some form of 'Songs of the Faith Anthology'.

Not only is the choice of familiar music and Scripture a point of agreement within the clergy, but the survey also indicates using the BCP service as a liturgy, or some abbreviated form of it, is still preferable to more modern liturgies. Over 80 % of the responding clergy noted how the "old familiar words" found greater welcome in Care Home Facilities. One of the reasons for the clergy's use of the "old" Prayer Book is that many of the residents grew up with it. Because of this, 50% of those who responded believe that residents receive "sacramental comfort" through the recitation of these familiar words, "waking up" as these words resonated with something deep within them.

Along with some of the anticipated responses to the survey questionnaire, there were some revelations, particularly in regards to the clergy's struggle to come to terms with authentic Christian community when Alzheimer's disease and other forms of dementia are present. Most clergy, for example, found little difficulty in discussing some of the

practical matters around care home services but, as the discussion drew closer to the Alzheimer's individuals themselves, there was a higher level of discomfort. Nearly 50%, for example, used phrases such as "only consecrating the elements during the service when there was a clear sign that the physical state of the person was ok". Other clergy, 52%, remarked that they chose not to consecrate the elements and instead use reserved sacraments because it was more 'convenient'. A high percentage also felt that keeping the service shorter was a necessity because of the care facility's own scheduling concerns. These observations give the appearance of needing to do the ministry as quickly and efficiently as possible.

Language usage was an interesting factor in expressing personal levels of comfort on the part of the clergy. Several times the care home residents, and specifically those who were known cases of Alzheimer's patients, were often referred to as "old dears" and "precious old folks". Some clergy commented that the 'ministry of presence' is not specifically appreciated as family and friends often assume that 'old Sally' and 'old George' may not recognize those who may be visiting, or they may even have difficulty grasping their immediate surroundings. One survey questionnaire even referred to the residents as 'inmates'.

There were additional interesting insights. In the last segment of the survey, this question was asked, "Overall, how would you rate your effectiveness in doing ministry with persons who have Alzheimer's disease and other forms of dementia?" Of the clergy responding to this question, many felt that they were effective in this area. However, their

answers to the following question, "On a scale of 1-10, what is your comfort level in this area?", revealed that the level of comfort was relatively low as if to suggest that a struggle, on the part of clergy, in this area of ministry is "ok". Finally, when the clergy were asked if a 'model of ministry' would be helpful to them, a few felt that they could benefit by being shown "a more effective way of reaching people", but most were more positive about the idea of a 'workshop' in this area, especially one available to laity and pastoral care volunteers.

These responses, I believe, are very telling. First of all they indicate a certain level of discomfort felt by people who minister in Care Home Facilities, particularly if some of the residents have forms of dementia. To some degree, this is understandable as not everyone believes themselves to have the specific gifts required of this ministry. However, this survey raises some very important issues around our understanding of personhood as it relates to our journey with the Alzheimer person. This journey should be one of *solidarity*. Our Christian vocation is to come alongside persons who are frail and infirm, reminding them, through the various gifts we offer, that they are expressions of God's presence. Not only do they name their present reality, they remind us of our own value and worth as human beings. Unfortunately, when the focus is on 'time frames' in worship, the power of the gifts is lost. Our constant call, as clergy and other leaders in this area of ministry, is one of accepting the challenge to move beyond *forms* of worship that *we* can use so that *we* can connect with people, and instead, cultivate a willingness to enter into a conversation that speaks of our *common* journey. Furthermore, we need to be aware that this journey involves a 'ministry of presence'. An intentional choice has to be

made to walk alongside those who are frail, rather than relying a 'program or workshop' in the hopes it will alleviate "the problem" and absolve us of having to engage.

As I place these observations alongside an attempt at creating an effective model for a Eucharistic rite for persons with Alzheimer's disease, one thing that stands out clearly is the need to see both the gifts of the church, and its leadership as being elements for life enhancing change. For this to occur there must be a visible willingness, on the part of the clergy and leaders, to stand in solidarity with care home residents. It is one thing to offer suggestions about the specifics of hymns and readings, and to pursue a liturgical model that allows a service a "natural flow" so that participants might have a spiritual experience. It is quite another thing, however, to allow the various gifts - whether they happen to be ritual, prayer, music, or the Eucharist - to be conduits through which the frail might express something of their needs and their abilities to the wider community. In the past there have been many well thought-out liturgical models proposed which have focused on the specific elements in an 'Order of Service'. These models have relied on suggestions regarding the length of service, the simplicity of the hymns and readings selected, and possible suggestions for parameters for preaching. These models do not suit our purposes. Our primary concern is reconnecting with liturgical forms that help us make sense of our reality so that our experiences of "life" can be legitimized. This is a model based on the Eucharist. David I. Kertzer in his article entitled "Legitimacy and Mystification", would mirror this understanding by stating that "the gifts of the church that are reclaimed are important events of channeling emotion, guiding cognition and organizing social groups. In so doing they claim to be powerful illustrations within the

life of ecclesiastical communities".[xxxv]

One way of giving support to this model would be to revisit the historical roots of the Eucharist, seeing it as the agent change it became when Jesus first introduced it to his disciples. For our purposes, we will focus on the words of institution in the Canadian Book of Common Prayer.

> *"... who on the night that he was handed over to suffering and death, took bread and gave you thanks, saying, 'Take, and eat: this is my body which is broken for you'. In the same way he took the cup saying, 'This is my blood which is shed for you. When you do this, you do it in memory of me... "* [xxxvi]

These words, or variations of them, have played a formative role in the church's history of providing the central meal for its followers. These words allow a glimpse of the world Jesus entered; that transformative movement of God which occurred to bring hope and liberation to all people. The Gospels remind us that this Eucharistic meal, this bread and this wine, was the final nourishment Jesus shared with his disciples. It remains a reminder of his everlasting presence and the freedom won through his selfless sacrifice. These words also reveal the deeper reality of the mystery of the *church* as a Messianic movement called out to assist in this liberation work for the freedom and hope of all persons.

From this we can clearly see that the original intention of the ritual of the holy meal was not solely about providing early believers with a 'strengthening symbol' or to identify a 'gathering point' on which to build a support network for the church community itself. The world that gave birth to this Messianic society was one heavily

influenced by Jewish and Greco-Roman ruling classes who had specific political, economic, and religious agendas that were often pursued at the expense of the common person. Various personal freedoms and rights were at stake in the face of these dominant cultures. The introduction of the holy meal was also an intentional counter-culture action radically different from prevailing social practice, and meant as an alternative model to the values of the predominant culture.

Under the influence of Jesus' teachings, this Messianic movement began its efforts to turn the tide regarding the practice of social stratifying, offering a new and progressive approach – seeing all human beings as persons of value and worth. It was a radical departure from the fundamental nature of the established sociological order of the day. As Larry Miller describes for us in his book, The Church as a Messianic Society, the earlier Christians provided an atmosphere differing from the social norm and engaging all aspects of life. According to Miller, it provided "alternative peoplehood, alternative friendship, alternative family, alternative politics, alternative economy, alternative education, alternative ritual, and alternative festivals...hence, Messiah's followers were to live life in another manner than it was normally lived in macro-society". [xxxvii]

Rapid development of early Christian communities saw this new "alternative" way of living become, as J. Hoekendijik describes it, a *centrifugal* mission. This word is descriptive of what happens when a close-knit community begins moving in an outward direction, thus allowing for its influence to reach the widest possible spectrum. Jesus' mandate would not allow early Christian communities to be inward looking social

networks, functioning on a level of survival and building walls between themselves and the rest of the world. Instead, they were called to take the message of light and life into the darkest corners of the known world. Their sharing of the Eucharistic meal provided a much needed model of hope for a broken and dying world. In his article entitled, "The Church Inside Out", Hoekendijk suggests that the initial community "leaves Jerusalem and the Jewish group and is on its way to the ends of the earth and the end of time. To join means here: to join the journey away from the centre. The symbol is the light for the Gentiles, which goes forth toward the people, seeking them out and taking them by surprise in their darkness". [xxxviii]

Once the early church was established, around the middle to the late second century, the practices and purposes of the Eucharistic rites came into question. This was partially due to the struggles being experienced by the church as it attempted to define ecclesiastical powers, the ordering and responsibilities of its clergy, and the church's role within the rest of society. The age of the centrifugal mission that Hoekendijk referred to, appeared to become stifled by institutional roles and ecclesiastical polity. What was once a means of offering liberation was quickly coming under the threat of becoming a captive of legalism. Restoration meant an intentional return to the original intentions of Jesus' holy meal.

Reflecting on the formation and evolution of the Eucharistic rite, reveals a struggle the church has remained engaged in to this day. The Eucharist of the original Messianic movement was seen as having the power to change the human situation and offer hope

and promise to a people living in times of adversity and uncertainty. As one revisits the church's mandate to offer freedom and wholeness to all people, one is called to reflect on the effectiveness of such gifts, particularly as they speak to the needs and concerns of modern day communities. The responses to the survey questionnaire reveals this tension wherein the power of the gifts of the church is seen as being diminished due to a chasm that has been created between ourselves and the people to whom we minister.

We must ask whether or not present structures and models speak to the *reality* of our ageing population, and particularly to those suffering from forms of dementia. As "church" we are called to stand in solidarity with those who have become a part of the marginalized segment of society. Do our practices, in regards to our use of the gifts of the church, bring us in line with the original mandate first introduced by Jesus, of offering both hope and liberation? Do our present liturgical rites embrace and acknowledge the life and value of the elderly-infirm person, particularly those who suffer from varying degrees of Alzheimer's disease and forms of dementia? Our experience and research reveals we do otherwise. Instead of affirming the ageing person and providing protection and support against societal views on the infirm, our practices appear to focus on the sacrificial, the elements of the ancient rites that strongly suggest "salvation as a past event - thus, once and for all", so that persons in their present journey can find little, if any, hope while they remain alive in this world. Salvation, therefore, is only seen as a "future event", available in the after life, but *not* now. Not unlike the struggling second century church as it attempted to understand the place and purpose of the Eucharist, today's church gives more weight to the role and power of the clergy instead of the gift

and the value of the individual. Is it any wonder why, in our present faith communities, there is such a thirst for renewal and hope for people who are marginalized?

Keeping these questions in mind, let us now focus on the model of ministry. To assist with this, we will use two local care home facilities in the city of Campbell River where I presently have pastoral oversight; Sunshine Lodge and Yucalta Lodge. These two facilities fall under the governance of the Vancouver Island Health Authority, an agency of the province of British Columbia's Ministry of Health. They provide long term care for approximately 200 residents, many of whom suffer from varying degrees of Alzheimer's disease and other forms of dementia. As an agent of change in these settings, the design of an appropriate Eucharistic model could not be begun without a glance into the 'physical world' of the Alzheimer individual. What do these institutions look like? As one enters either of these two facilities, one is struck by the fact that one has entered into an institution designed for the care of persons with chronic health concerns. The interiors of both buildings have been painted off-white or near yellow in the hopes of giving the impression that they are less of an institution and more of a home for their residents. Along the corridors one can find the typical accumulation of therapeutic equipment including wheelchairs and lifts needed in order to make that transition of each resident into the daily routine of activities as easy as possible. Most of the walls contain pictures of nature and scenery reflective of the local community. There are several pieces of native artwork on display in the common room at Yucalta Lodge, for example, that acknowledges Campbell River's First Nations Community. There are also several wood carvings of the pacific coast salmon situated on the fireplace mantle-piece, reflecting the

city's long history in the fishing industry. The walls in Sunshine Lodge are also covered with a variety of pictures, many intentionally seasonal thematic celebrating Thanksgiving Day, for example, or Easter. Because this facility offers various art and craft classes, pieces of the residents artwork are also put on display just outside the main dining room area.

In addition to the general domestic features of these two care home facilities, one finds other ways in which residents are made to feel "at home" and still connected to their pasts and their families. This has to do with the residents individual rooms, where they spend most of their time. Visiting the living quarters of a parishioner named Bill (not his real name) it was obvious to me that Bill's wife had gone to a great deal of effort to have his room resemble the home in which he had spent so many years. It was interesting to see a collage of family photographs, celebrating various stages of their lives together, hung on the wall just next to his bedside table. There was even a picture of Bill in his former working environment, a local woodworking factory, where for 35 years he used his gifts as a carpenter.

Overall, one of the major impressions that one gets upon visiting either of these two care home facilities is that a real attempt has been made to create, for the residents, a homely environment that is both comfortable and familiar. In spite of this, as both are government funded Health Authority facilities, one is also aware that these are still "hospitals" with many of the typical reminders of the sterile environment that have been part of the recognisable hospital atmosphere for decades. One cannot get away from this

reality.

As much as an attempt has been made to make the world of the Alzheimer and dementia person as "normal" as possible for the residents of these care facilities, we are still faced with the challenge of seeing how things "really are" for most of them. Jean Clayton, in her book entitled The Tiny Red Bathing Suit of Mr. July offers helpful insights into some of the realities of limitations on choice for persons entering long term care facilities, even if they are modernised as are the two I described. She describes these as *losses* of the human condition. When people come into a care home, particularly those who have forms of memory loss

> "there are further losses: privacy, their home environment, and, to a large degree, access to their family. They may be required to wear diapers and take laxatives or enemas on a regular basis. They may be moved from bed wheelchair by being swung through the air on the canvas sling of a Hoyer lift. Residents may be given medication without discussion, including tranquillisers or sleeping medication. Their choice of meals may be limited or non-existent. If they cannot feed themselves, they may be fed too quickly by too-busy staff, so that eating becomes stressful rather than pleasurable. They have to go to bed and get up at the convenience of others. They may or may not have a TV, radio or telephone available to them. They may have little or no influence on the temperature of their room, and must depend on the kindness and patience of others, for almost everything. Having a cup of tea when the mood strikes, or getting up to watch a favourite program on TV and eat buttered toast when they can't fall asleep becomes a wild and unlikely dream". [xxxix]

Jean Clayton's words are worthy of our reflection as we search for a ministry model which mirrors the early Christian community's attempt to live out the mandate of a Messianic society. She reminds us of some of the harsh realities people face once they

succumb to the world of Alzheimer's disease, and when they end up living out their days institutionalised. Due to the severity of the disease, and the fact that they require a level of care few families can provide, many have no choice but to accept placement in these facilities as soon as space becomes available. Furthermore, as individuals move through the phases of neurological impairment, it is taken as a given that they can no longer speak for themselves nor can they make decisions that would effect their own lives. They become a people who have no voice. Clayton's work is valuable for another reason, as it gives us permission to speak about the real lives of real people. She reminds us that those who are institutionalised are not simply people that have no past or history. Rather, they are living, breathing human beings who have families of their own, and who have done much in their earlier journeys to contribute to the society we continue to enjoy.

Perhaps these powerful reflections of hers offer a key to opening up the gift of the Eucharistic liturgy, bringing it closer to the intents and purposes of the holy meal of the original Messianic movement as taught by Jesus. Reconnecting with the idea that original faith communities understood the power of liturgy as a conduit to the creation of a counter-culture society, one might draw the conclusion that such Eucharistic practices were designed *to speak out* against the injustices of the day while reminding the wider community that all persons were to be seen as having value and worth. Raphael Avila, in his article "*Worship and Politics*", offers that "the power of the Eucharist is to be found through a measure of crises or judgement that it evokes within the given society. Whenever a Eucharist is celebrated, there is a challenge being made to the church to recognise a profound event going on in the lives of people, that the injustices and

oppressions within the wider community have now been uncovered". [xl] The action of *provoking a* crises through this "uncovering" by way of the Eucharist, is a form of truth-telling. Situations thought hidden, are revealed in the light of the Eucharist. Avila further offers that the Eucharist, "has to be seen as an intentional political sign so that its members vis-à-vis the church - will recognise the relationship between the church itself and the various socio-political forces that are in power at any given time". [xli]

Avila's article sites the example of the work of several bishops within the Latin church in Central America who were taking a critical look at the influence of the Eucharist as it is lived out in many of the local parishes. The Latin bishops came to believe that the Eucharist was seen to have qualities that were two-fold. First, there was a direct link made to the memorialising of Jesus' passion and suffering. When, for example, Jesus said to his disciples the words "do this in memory of me", it was to invoke the understanding that God had entered the world as one who had come in the form of the suffering servant, making the declaration by taking the journey to the cross. Second, they saw the Eucharist as being an expression of a *progressive movement* in peoples' lives. In essence, the Eucharistic rite also has a quality of being eschatological. As Jesus was raised up on the third day, the Eucharist further awakens people to the reality that *they too* are participating in the eschatological workings of God as a people who have themselves been raised up. According to the bishops in Avila's study, this is the meaning of Jesus' words in the Gospels, "God has raised Christ from the dead, and also therefore all who believe in him. Christ, actively present in our history, foreshadows his eschatological action not only in the impatient zeal of humankind to reach total redemption, but also in

the conquests that, like prophetic signs, are accomplished by human action inspired by love".[xlii] It became obvious to the bishops that the people of God, in Latin American communities endured years of oppression and abuse under European domination. What has come out of this, however, is that the Eucharist became a visible sign of hope for these people, by making their history of oppression a truth revealed. Hence, the *crises* or judgement is made known.

The work of Rafael Avila challenges us to see a similar power within the Eucharist whenever and wherever it is celebrated. In a local context, how would the language *we* use when celebrating the Eucharist provoke a *crises* or *judgement* statement within the present structures regarding the common needs and concerns of the elderly? Are there components in the liturgy that speak directly to the socio-political forces governing our world and forces whose action, or lack of action, could have a direct impact on our ageing population, particularly those who are institutionalised and suffering from forms of dementia?

Having raised these questions, we are ready to take the next step and consider a model of ministry, in the form of a Eucharistic rite, that would call the church to stand in solidarity with the residents of care homes, to uncover their truths, and to give a voice to the voiceless. What would this model look like? How would it be representative of the life and community of persons who live in Yucalta Lodge and Sunshine Lodge? How would it both offer itself as a sign of hope and as an opportunity to raise a crises or political statement to the wider community? This is our attempt.

A SERVICE OF HOLY EUCHARIST

For use in Care Homes and Institutions

Opening Hymn

Priest: *The Peace of the Lord be always with you.*

People: And also with you.

Collect: *Loving God, you have made us as a people of value with open hearts and with desires that are known by you, even though we may have difficulty in sharing these truths. Gently offer your cleansing mercy on us through your Holy Spirit, that we may perfectly love you, an always know that we are in your service and under your care. Amen.*

Scripture Reading

Homily (*Comments or a brief reflection may be made at this time*).

Introduction to confession

Priest: "*Lord you have given us the gift of familiarity, when you have given your servants down through the ages, the words with which to offer our prayer of confession to you, and in so doing we can hear as well, your reminder to us of our forgiveness. We say these words together now:*

The Confession continues according to the standard form in the Prayer Book

The Confession (said by all)

Almighty God, Father of our Lord Jesus Christ, Maker of all things, Judge of all: We acknowledge and confess our manifold sins and wickedness, Which we from time to time most grievously have committed, By thought, word, and deed, Against thy Divine Majesty. We do earnestly repent, And are heartily sorry for these our misdoings. Have mercy upon us, most merciful Father; For thy Son our Lord Jesus Christ's sake, Forgive us all that is past; And grant that we may ever hereafter Serve and please thee In newness of life, To the honour and glory of thy name; Through Jesus Christ our Lord. Amen.

The Absolution

"*Almighty God, you have promised your mercy and forgiveness to all who turn to you in faith and repentance. These have been your words of love since the very beginning. Have mercy on us, pardon and deliver us from all our sins; confirm and strengthen us in all goodness and bring us to everlasting life; through Jesus Christ our Lord. Amen".*

Hymn

The Sursum Corda and Prayer of Consecration

Priest: *The Lord be with you*

People: And with thy Spirit

Priest: *You have invited us, as a people who are one with you to lift up our hearts to you.*

People: We lift them up unto the Lord

Priest: *You have invited us, Lord, as a people of value and worth to offer you our thanks and praise.*

People: It is meet and right so to do.

Priest: *You have called us at all times to give you thanks, especially with your promise that you are with us in our earthy journey. Indeed you are with us at all times and in all places. We therefore give you thanks, along with the whole company of heaven, and where you invite us to say:*

People: Holy, Holy, Holy, Lord God of Hosts, Heaven and earth are full of thy glory. Glory be to thee, O Lord Most high

The Prayer of Consecration

"O Lord, our creator of heaven and earth, you have made us in your own image and we have been made worthy individuals in your sight. You have created us as unique individuals. You have reminded us that through our common frailty we have a connection with your life and witness. As you first ministered with your friends, you gave them, through the promise of your Spirit, the knowledge that you would be with

them in every daily struggle, and that this would be lived out until the end of the ages. In so doing you have brought to our remembrance that our daily lives are often filled with uncertainly, but not without hope. In the world of limitations, this aspect of human suffering has become, for us, the appearance of an unwelcome guest. We feel the absence of what we once were. We feel the decline of our memories, our lack of judgement and changes in our learning ability. We discover things about ourselves that we no longer have control over. We notice irritability, sudden mood changes and restlessness in our inner being. Agitation and anxiety have now become a common way about us.

Our own world now is also vastly different to what it once was. The pictures in our rooms, of our families and friends, help to both remind us that we have a sense of identity and a belonging to something larger. They connect us with those things that are familiar. Through them, we remember that we are living people who have had, and still have, lives of value and worth. They help to rekindle our past experiences and the contributions that we made for the benefit and upkeep of your world.

We also notice the walls and other rooms of this facility that help us in our connection with the wider community. We find that they are filled with images of the creativity of peoples abilities, and the wooden carvings offer a symbol for us of our part in the local area. The carved West Coast salmon and First Nations Artwork say to us that we come from a rich heritage of a blessed people. Furthermore our day to day surroundings help to remind us that these care facilities are places where people are not forgotten about, and they remind us of the constant struggle to be seen as people of worth, and the constant need for the witness of this to be made known. Ultimately, this is the hope that you came to establish.

Therefore, on the night in which your Son Jesus was betrayed and gave himself up for solidarity with humankind, Jesus took bread and gave you thanks, saying "take this all of you and eat it, this is my body which was given for you, and which has come to bring both life and hope to this hurting world"... Afterwards,

Jesus took the cup of wine, said the blessing and gave it to his friends and said, "All of you drink this, for this cup is the fulfilment of the covenant in my blood. Those who do so, share in my vision for the restoration of all people, and offer release from bondage all who suffer.

We give you thanks, that we can present these powerful signs of bread and wine as nourishment for us, and for the nourishment of all people who are frail. We ask that your Holy Spirit may enter these gifts so that they may become for us, the unifying sign of our solidarity with you, and as your church continues to witness to this reality in the lives of all of its people. Finally, in the fullness of time, may this holy meal continue to offer an ongoing hope that was first made known on the very night in which Jesus was betrayed, that every human creature under heaven and on earth may share in the banquet that you have promised, and that unto the end of the ages, our solidarity may be lived out in the lives of all your people. All glory is yours Almighty God, through Jesus Christ, his Son, Amen".

(The Administration of the Sacraments of Bread and Wine)

Priest: *Let us again be reminded of the love that God has for all of his servants in the words of the Lord's Prayer, as we say together*

"Our Father, who art in heaven
hallowed be thy name,
thy kingdom come,
thy will be done,
on earth as it is in heaven.
Give us this day our daily bread.
And forgive us our trespasses,
as we forgive those who trespass against us.
And lead us not into temptation,
but deliver us from evil.
For thine is the kingdom,
the power, and the glory,
for ever and ever. Amen.

The Prayer after Communion

> "*Loving God, we continue to be reminded as we have received this bread and wine, that we are forever in your remembrance, and that our day to day struggles are not forgotten. We also are reminded that our participation in this holy meal is a sign that we are living members of your body, and we continue to be a part of your church. We are therefore presented to you as whole, loving people in your sight who continue to remain in your service. Amen".*

The Blessing "God of love and mercy, we are the signs of your presence in the world. May we continue to be seen as agents of this love in all that we do. And may the blessing of the God who creates, sustains and empowers us; Father, Son, and Holy Spirit be with us this day and for ever more". Amen.

Closing Hymn

From this model of ministry in the form of a Eucharistic rite, we can make the following observations. We are reminded that whenever one offers any form of ministry in a care home facility, one of the components is an acknowledgement of the familiar. We see examples of this with the mention of the surroundings of the care home and the *articles that are* spoken of in the residents rooms, both of which are in place the in the prayer of consecration. Experts tell us that in presenting familiar things to residents decreases their level of anxiety, and, at the same time, bridges many of the emotional gaps which often occur when people are committed to the care of such facilities. They find it a smoother transition when the world they are entering is as similar as possible to the one they have left. Some may translate this need for familiarity in their physical surrounding and a good argument for retaining a previously experienced order of service

the status quo anti, if you will. In many ways this tension is acknowledged in this model that recognises some aspects of the liturgy that are very familiar in terms of wording. This is why, for the most part, the responses from the residents are all taken from the familiar wording of the Book of Common Prayer. Furthermore, what is also being addressed in this model is the familiarity of the *natural rhythm* of the service itself. It is known, for example, that the absolution follows the confession, and the Lord's Prayer follows the Prayer of Consecration, and so on. However, in this model, making declarative statements within the Eucharistic rite makes space for the possibility of reconnecting with various forms which can help make sense of the *reality around us*, so that our beliefs about God and life, in all of its ways can legitimised. Our main intent, then to attempt to grasp the day to day world of the Alzheimer person, and in doing so, honour the original mandate of the Messianic movement as introduced by Jesus.

What is gained, for example, from the following verse in our revised prayer of consecration?

> *"In the world of dementia, this aspect of human suffering has become, for us the appearance of an unwelcome guest. We feel the absence of what we once were. We feel the decline of our memories, our lack of judgement and changes in our learning ability. We discover things about us that we no longer have control over. We notice irritability, sudden mood changes and restlessness in our inner being. Agitation and anxiety now become a common way about us."*

Here a clear statement is being made about the *real* lives of real people suffering forms of dementia. Mood swings and altered personalities are some of the day to day realities faced by these individuals. According to literature produced by the "Interior Alzheimer

Foundation" of Kelowna, BC, in Canada, diverse psychological changes are a very real issue for the lives of those struggling with Alzheimer's disease. "The Alzheimer person goes through a variety of psychological changes in a given day. The individual is often characterised as a person with declining memory, judgement, and learning ability. Irritability, sudden mood changes, restlessness and agitation may become common. Personality changes occur with a breakdown in speech and language, increased confusion and inability to carry out routine personal care".[xliii] The life of the person suffering from this disorder is impacted by monumental losses that range from personality changes to limitations in personal judgement. Their plight is clearly defined.

As a model for ministry, this Eucharistic rite speaks to the issue that, in all aspects, human life has value. It affirms for people that their vocations, occupations and personal accomplishments are not lost due to the fact that they have succumb to a disease of loss and limitation. As the prayer of consecration in this rite suggests, every care home resident has a past, they each have a history. Their lives are compilations of milestones and events with family and friends. They have ties to the community.

> "*Through them, we remember that we are living people who have had, and still have, lives of value and worth. They help to rekindle our past experiences and the contributions that we made for the benefit and upkeep of your world".*

In the final section of our prayer of consecration we find the heart of this ministry model.

> *We ask that your Holy Spirit may enter these gifts so that they may become for us, the unifying sign of our*

> *solidarity with you, as your church continues to witness to this reality in the lives of all of its people".*

Just as it calls us into unity with God, so too does the liturgical work of the church call us to stand in solidarity with those who are suffering and marginalized. No longer are they voiceless. They have someone, the church, who can speak their pain and offer their reality as a means of judgement to the wider community. So begins this journey towards emancipation.

Reoccurring throughout the framework of this new model is the mention of *crises* – something which, should one do a comparative study, would be found to be lacking in many of the Eucharistic rites presently in use. This leads us to question their power and effectiveness for our purposes. This lack of *crises* points to a theological shift which became the norm by the time of the Early Church and which is still in evidence today. The Prayer Book rite offers an example of this as it speaks exclusively of the *sacrificial* offering of Jesus, as it was proclaimed by God, for the salvation of the world:

> "who of thy tender mercy didst give thine only Son Jesus Christ to take our nature upon him, and to suffer death upon the cross for our redemption; who made there by his one oblation of himself once offered, a full, perfect, and sufficient sacrifice, oblation, and satisfaction, for the sins of the whole world; and did institute and in his holy Gospel command us to continue, a perpetual memorial of that his precious death, until his coming again". [xliv]

This prayer does not give weight to the eschatological co-operation that exists between God and humanity spoken about in the work of Rafael Avila. The Latin bishops

he wrote about suggested that Jesus' passion must also be seen as a *progressive movement* in the lives of people. The very fact that Jesus was raised on the third day awakens a poignant reality in the Eucharist. When celebrating this holy meal, God's people participate in this event as a resurrected people. It is through this redemptive work that *all* of God's people – *the church* – work together to dismantle the forces that work against God's ultimate plan of salvation.

One may draw the conclusion that the church which gave birth to the Prayer Book reveals a tension which exists even today. When one considers the Early Church, there appeared to be a greater acceptance to embrace the counter-culture movement established by Jesus which saw the work of the church as a means of promoting liberation and justice. Church life and ecclesiastical polity had a focal point on the *common* person. It wasn't until several centuries later, during the time of Charlemagne, that a chasm began to form between the institution of the church and her people. During this time the church became almost identical *to* society, making greater the challenge to work against oppression and to unmask forms of abuse within that society. One subtle reminder of the church / society integration during this period was the wearing of vestments, a 'tradition' clergy 'borrowed' from those in authority so that they too might be seen as figures of authority. The result of this was that the clergy began viewing themselves as having a stature similar to that of community leaders, the very people they were often opposed to politically. Ironically, this perception continues today.

Our conversation around existing Eucharistic rites is not merely to draw comparisons

between past and present practices; we still must question their lack of sufficiency for some segments of the Christian community. A new Eucharistic rite is not made complete by mere mention of *crises.* It cannot just reveal the plight of those who suffer from Alzheimer's disease and dementia. Nor can it simply allude to the increasing risk to people unable to speak for themselves, or stripped of value and power because they happen to suffer from a degenerative neurological disorder. Such revelations must lead to action. One is reminded of how the power of the gifts of the church can easily be forgotten. As Rafael Avila reminds us "that there is nothing more dangerous than an unrecognised power, because one who has the ability to make political change without knowing it is an easy victim of manipulation". [xlv] To forget this would be an even greater tragedy.

The potential of a new Eucharistic rite becoming a vehicle of transformation was brought home to me through the choices and actions of a parishioner who is also employed as a Nurse at one of the care home facilities. Having expressed an interest in my work, she allowed me to share my thoughts and ideas regarding the creation of a Eucharistic rite that would speak to the lives and needs of the elderly and infirm, particularly those with Alzheimer's disease and other forms of dementia. She commented that, "in such a Eucharistic rite, there would be parts of the service that residents would be able to associate with as the liturgy stressed, to a large degree, the present moment for people who were in various levels of medical care". I learned, later, that our conversation sparked an in interest that led her to begin a campaign of letter writing to her superiors and local and provincial health care authorities regarding the level of care many care

facility residents are presently receiving in the province of British Columbia. Naturally, this was done with a high level of professionalism so as not to put her employment in any jeopardy, nevertheless, she felt moved to become *an advocate* for the patients in her care. At the present time, both Sunshine Lodge and Yucalta Lodge have undergone a tremendous reduction in funding as have many of this provinces' care facilities. There are concerns about understaffing and reductions in the amount of quality of the care being provided. On an average 12 hour shift, residents receive only a minimal level of medical attention, except for feeding, and the distribution of prescribed medications, and assistance with basic personal hygienic care to the residents. There simply aren't enough staff members to go around. The nurses are doing their very best, and are to be commended for such efforts, but they have only limited resources with which to work.

As one would imagine, the needs of care facility residents, especially those with dementia, the needs are ongoing. After reflecting on our conversations about the liturgy, this nurse decided to advocate on behalf of two of her patients in particular. Both are elderly women, ages 82 and 92 respectively, and both need constant assistance as they spend their days in wheelchairs and are confined to their beds the rest of the time. The nurse informed me, however, that during a recent period of staff shortages both had been confined to bed, on their backs, for several days because there simply wasn't enough assistance available to transfer them to new sleeping positions. This resulted in one of the ladies experiencing an increased level of bed sores and other medical complications. Since my initial conversation with this nurse, every time I now enter this facility, I receive an updated report of how these two residents are doing. From my perspective, it is

a delight to see how my parishioner's role as an advocate has taken her to a new level of service in her work as a nurse in the health care system.

Reflecting on this situation, I am keenly aware that as in the story of these two elderly ladies, neglect is a common problem. It is also a reminder to us of the constant need to both examine, and re-examine, the important gifts of the church which can be agents of change in the world. One wonders if the role of advocate taken by this nurse, mirrors the role taken by the early Christian communities who operated on counter-cultural intentions while following the model of Jesus offered as a way of bringing hope to the wider community. Her own activism, through her letter writing, was indicative of an understanding of the model Jesus left with us. She responded to the crises in a way that was voice restoring and life giving, counting the elderly and the infirm amongst God's valued people. In calling the rest of the community to attend to these, she was also reminding them that they too, as potential "ministers" in this situation, are valued people of God. This gentle gesture of advocacy is a real example of the gifts of the church as profound agents of change. "The status quo is challenged in order to provoke a change in thinking and action....it is not to give sin an opportunity for making a formal entrance into society, but rather to judge it and to unmask it. If we are ingeniously unaware of the accused or if we refuse to judge them, this is not prophesy and it quickly dissolves the tension that should be celebrated. It negates hope and remains caught in the trap of positivism". [xlvi] As Avila contends, responding to the prophetic crises in our common call. This, I believe, is what this nurse was attempting to do.

When one visits the deeper realities of the gifts of the church, one comes to understand that not only do they feed God's people, they also initiate holy actions. They offer what was at the very heart of the Messianic movement initiated by Jesus, as a way of bringing God's fulfilment into the present day. Exposure to this understanding reminds those offering ministry through their care of persons who are vulnerable and marginalized, of the sacred vocation to use the gifts we have been given – and use them wisely – as a means of offering hope to, and solidarity with, all of God's people. Furthermore, it would also serve as a significant step in our journey towards a deeper understanding of a theology of personhood.

Chapter Five

This exploration of the world of the Alzheimer individual has been a profound and insightful experience. My visits with my parishioner "John", with whom I began this journey, and the pastoral relationships I subsequently developed with "Jane" and "Margaret", initiated question after question regarding the church's place and purpose in the lives of those with Alzheimer's disease and other forms of dementia. Gradually my search expanded to an enquiry in to the nature of "personhood" and how God affirms and sustains the "personhood" of the Alzheimer individual through the workings of the gifts of the church. My pastoral ministry resulted in opportunities to witness God's movement in these people's lives. In John's case, specifically when he received the Eucharist, I observed a change wherein it seemed as if God was revealing his nature, as a Divine being of ultimate love, through this offering of the gifts of the church. This led me to ask, "What was going on when John received these gifts?". It occurred to me that John was experiencing an "awakening" when he received the Eucharist. For brief periods he would move from a near comatose state to a state in which he became more *alive.* Furthermore, when he received the Eucharist he kept repeating the word "Amen" over and over again. These episodes led me to conclude that the gifts of the church provided a window through which effective and life sustaining ministry might be offered to those living lives being drained away by the diminishing effects of Alzheimer's disease and other forms of dementia.

As this journey continued, however, I came to realize that the parameters of my

question were broadening. The shape of the question grew from, "What was going on?" to more specifically, "What was John *saying* when he had this experience of sharing in the Eucharist, or when other of the church's gifts were offered to him?" Was John inviting us, for example, into some form of dialogue about personhood? Was he inviting us into a conversation with him that informs us that degenerative disorders, such as Alzheimer's disease, does not constitute a "loss of self" but, instead, offers an invitation on the part of the Christian faith community to assist in the "recovery of self"? I believe he was.

As well as continuing to accompany my own ministry, these questions have instigated reading and research that has given me new insights into the power of the gifts of the church and what they offer to persons suffering Alzheimer's disease and other forms of dementia. Some of my own observations and also those of my colleagues, have suggested, for example, that the gifts of the church have the ability to connect with people on a profound level offering, not only a renewed understanding of themselves, but also of the world around them. They invoke change and transformation. Others from the theological and academic world also echo these insights. David Hogue's book entitled Remembering the Future Imagining the Past: Story, Ritual and the Human Brain, is brought to mind in which he presents extensive research, from the perspective of faith communities, on the ability of ritual and other gifts to offer hope to persons undergoing periods of stress and trauma in their lives. In his research he cites the conclusions of family therapist Peggy Papp who suggests that ritual, and other gifts, can be paramount in helping families though life altering situations. "Ritual in all of its forms can be used

when ministering to persons not only to comment on the experience, but to actually change it. Since Rituals and other gifts of the church, make use of the stuff that dreams are made of - symbols, fantasy, myths, story telling and metaphors, they address themselves to the most primitive and profound level of experience". [xlvii]

Furthermore, *other fields of study* would support this idea. Cultural anthropologists Robert McCauley and E. Thomas Lawson in their book, Bringing Ritual to Mind: Psychological Foundations of Cultural Forms have offered intriguing insights on ritual and its power through their observations of the Baktaaman peoples of central Papua New Guinea. During the latter part of the 1980's, McCauley and Lawson concentrated their work on examining the initiation rites of male individuals who, after a period of time, began to show a remarkable inner understanding of themselves and their own identity as members of the Baktaaman community. The Baktaaman are an indigenous group of people who, prior to the early 1960's, had little if any contact with the outside world. They are a small, illiterate group who number no less than 180 people, and whose very sustainability is the result of hunter gatherer techniques and some subsistence farming. McCauley and Lawson observed that the Baktaaman peoples exhibited very interesting initiation rites for males which, when completed, bring them into full membership and stature within the community as men. Through this process they ascend through seven degrees, or levels, of initiation rites. However, because of the high level of scrutiny and secrecy within the group, the details of the rites themselves are somewhat sketchy. So secret, in fact, are some of these rites that senior members within the group threaten initiates with death should they violate ritual secrecy. Furthermore, not only are initiates

themselves prohibited from discussing these secrets with non-initiates, most of the time they are also prohibited from discussing them among themselves.

Even working within these parameters McCauley and Lawson were still able to make some observations of Baktaaman ritual. In doing so they made an important discovery regarding the reception of rituals by the initiating individuals themselves. The initiates enter into what the anthropologists call a form of "analogic coding" where a message of understanding about one's culture is transmitted from the senior member to the initiate. These initiations "transform a group of young persons into men who possess a general area of common sensibilities and intuitions and a range of understandings sufficient so its members can be moved by the same symbols and thoughts. The initiations instil in the initiate distinctive cognitive dispositions and sensibilities concerning self, cohort, society and Nature". [xlviii] Hence, the new members attain a deeper understanding about themselves, each other and the world around them. A further important discovery is the *way* in which this knowledge is retained and received, particularly when one considers that the Baktaaman have no concept of written language within their culture for they are still able to derive an understanding of themselves as a people.

Some of these insights have informed my research regarding the gifts of the church and their power. From my own observations, and from the experiences of my colleagues, I am led to believe, borrowing the language from McCauley and Lawson, my own that "analogic encoding" occurs with the practices we offer. Ritual instigates change. McCauley and Lawson's work also speaks to the depths reached using rituals and their

power. Quite specifically, when rituals - whether they be story telling or other - are done either routinely or over and over again, those who participate in them end up becoming *a part of* the story or script that is happening. This means, among other things, that they become habitual and automatic. In fact, "their memory for carrying out these action sequences is largely procedural rather than declarative. Participants may have a much richer sense of *how* to proceed than they have for *what* they are doing. Their knowledge is *implicit*". [xlix]

As helpful to our understanding of the gifts of the church as these observations may be, we must also be mindful of their limitations. When I revisit my enquiry with John and the others, I believe they are inviting us to see the gifts of the church as instruments of solidarity, allowing us to stand alongside those who have no voice. In reclaiming these gifts they participate in recreating community, reminding us that they are people of tremendous worth and value. The life giving and affirming language that is a result of sharing these gifts can be used as a means to identify, to the wider community, the profound reality of the Alzheimer person. To merely focus on the gifts as only providing brief experiential moments for the recipient, in this case the person with Alzheimer's disease, is a limited and potentially detrimental view. I am reminded of the responses of my colleagues on the survey questionnaire and the struggle endured while attempting to find a way of connecting with the Alzheimer person. At the same time, finding an order of service which "fits" the needs of that person. The tendency, it seems, is to concentrate on a means of allowing clergy to feel adequate as caregivers, but in a way that fits within a prescribed time frame, in order to keep the service as brief as possible. Because,

according to the voice of my colleagues, *keeping it short is vital.* The other struggle I encountered with was the request for programs and workshops which would help people learn more about ministry to persons with dementia and so on, which seem to suggest that we can do effective care and ministry *from a distance.*

To be sure, this may be a normal response to feeling uncomfortable especially if one does not enjoy such pastoral work in institutional settings. Yet this suggests a serious contradiction for the church because it speaks very clearly to the nature of personhood as a journey *in* community and the need to find authentic ways of *being* community. In many ways, John, Margaret and Joan have been instrumental in helping us formulate this understanding. When I reflect on their personal stories, I reach the conclusion that they have been inviting us into a dialogue that embraces a sense of "The Other". In our earlier chapters we noted the parameters that defines 'the others' in our society. They are those in our communities whose context is formed by persons holding positions of authority and power. They are the individuals or groups who are powerless and who others can systematically marginalize or oppress. The stories of John and Margaret and Joan invite us to enter their reality so that we might have a fuller understanding of the human condition. How might this be? Quite simply, their invitation is a call for persons to be *vulnerable* with one another. Seeing and accepting each other as full sisters and brothers engaged in the same journey.

In many respects it is easy to see the vulnerability in their stories. John endured a myriad of losses due to his entrance into the final stages of Alzheimer's disease. He

experienced a loss of cognitive function. He was unable to feed or dress himself. He also reached the point where he was unable to speak or smile. Margaret also went through a variety of losses. She struggled to find and maintain her place in the church community, a place now in jeopardy as a result of being clinically diagnosed with dementia. Jane's story was another path paved with losses. In her case it was 'language-statements', based on her age, that were becoming a determining factor in her ability to offer her gifts of music to the church. At the heart of our journey towards the practice of authentic ministry, however, is a call for a renewed vision of vulnerability – for *all* people. To be receptive, to be open to others and to be open to life requires a certain amount of vulnerability. We need to be honest about our fears, our thoughts and feelings. We need to speak of our own losses and failures. We need to speak with a sense of integrity about our dreams and our passions and our ideals and place them alongside our core values and what we believe about God and life. The philosophy of Levina mirrors this when he suggests that "subjectivity is vulnerability, it is having an exposure to 'the other' at the deepest possible level".[1] For any level of closeness, or for any authentic connection to be made, *we need* be vulnerable in the face of "the other".

This ministry of vulnerability, as Hubertus Ernst points out in his article *"On Being Human and the Human image of God"*, has scriptural support. We read, for example, the Apostle Paul, in his letters to the early Christians in Corinth, addresses the question, "What does it mean to be truly human?" Earlier on, Paul's experience had taught him that he was not able to make the radical attitude of service that Jesus had taught – a service unto death, even death on a cross – *understandable* to people. In Paul's own words this

concept seemed foolish to him. This was also the reaction of Jesus closest followers when Christ began this mission. The Gospel reminds us that even his family members and friends wanted to seize him and bring him back home because they felt he had gone out of his mind. Therefore, Paul offered a reflection on the subject which speaks to the "folly" of Jesus in contrast to the "wisdom" of the world, and accordingly we know God through this folly. Hence, the foolishness of God leads to the wisdom of God – a wisdom not comprehended by the those in authority at that time. As Ernst points out in his article, Paul also speaks in this context of God's weakness, calling the weakness of God, or the *vulnerability* of God, as stronger than human strength.

> *"For the message about the cross is foolishness to those who are perishing, but to us who are being saved it is the power of God. For it is written, 'I will destroy the wisdom of the wise, and the discernment of the discernment I will thwart'. Where is the one who is wise? Where is the scribe? Where is the debater of this age? Has God not made foolish the wisdom of the world? For since the world did not know God through wisdom, God decided through the foolishness of our proclamation, to save those who believe".*
>
> *(1 Corinthians 1:18-21, NRSV)*

As one can see, this further opens our dialogue, possibly providing a partial answer of what it means to be "truly human". Ernst goes on to say "we could say in this context that what seems foolish is in fact human. We could say moreover, that it is foolish and human for the same reason: foolish, because it is contrary to the self-centered striving for being (*conatus essendi*) as the philosopher Levinas once explained. Yet, human, because it is changing life from self-centeredness to dedication in response to the demand of the

Face of the Other, making the conscience-driven choice to be a neighbor to the other." [li] As Ernst would suggest, the ideas behind the writings of Paul seem far removed from real life but, when one looks at the interactions we make within our world, we find we can all can place ourselves in this picture Paul paints for us. After all, "does not everyone of us know moments when we say: what I have done is foolish, but I could not do otherwise? I had to do it".[lii]

This dynamic is played out in the affairs of everyday life and at the heart of it, is the conscious shift we make in order to widen our intentions to connect with the other. It is the movement from a self-serving perspective, to one of placing others within our field of vision. In other words I must be willing to place my own agendas and assumptions aside, and acknowledge my own fears, with the hope of gaining a deeper sense of the journey being experienced by those to whom I minister. I must be willing to have an *exposure to the other* at the deepest level. This, no doubt is one of the great tensions of all who honestly strive to be engaged in areas of pastoral ministry. It calls us to move beyond our own comfort levels, even laying aside our own assumptions of ministry, in order to communicate a Christ-centered model of freedom and liberation for all people. As suggested earlier, the danger is in the failure to see this. For me, a profound insight attained in this journey has been the discovery of my own assumptions when entering institutions to offer care to persons with Alzheimer's disease. My initial observations, of what I witnessed happening to John, led me to see the gifts of the church in a way that was, for the most part, *clerical* centered. I saw that John responded whenever the Eucharist was offered and because I was the ritual practitioner and had the means with

which to offer the sacramental presence to him, it would have been an easy step to assume that I enabled John to have this encounter with God. In retrospect it was also seen as an occasion of "the church" going in and doing the function of ministry so that it could somehow validate the effectiveness of the church in that ministry.

How did assumptions inform pastoral ministry in these critical encounters? They caused the ministry experience to stall at "provisional" rather than allowing it to progress to relational. It gave the impression that *we* have the gift of the church and *we* are in control over the given situation, and *we* have the means with which to dispense this gift so that *they* will experience God's presence. One can see the danger here. It is reminiscent of clericalism that is supportive of structures where someone has *power over* someone, and uses it in this manner. Historically speaking, this has been a recognized struggle for the church and, due to our ignorance, it has resulted in broadening the rift between those who "minister" and those to whom we've been called to minister. This raises questions about the mutuality of our encounters or, to use Ernst's words, making the conscious – driven choice to be a neighbor when faced with the Other in all of its manifestations. Ministry becomes mutual when we invite relationship to unfold.

What might John and Margaret and Jane's stories be revealing? What might they be saying to us? They may be challenging us to change our perspective and adopt theirs, for a time. In our society there are many people who operate as if they are on the outside looking in. They are not seen as full members of the community because the community has placed them into categories of powerlessness based on class, creed, orientation,

gender, ability, colour or age. In asking us to place ourselves in their positions – we discover the struggle of maintaining one's belonging in community and the struggle to maintain a sense of "self" in the face of diminishing language statements. John and Margaret and Jane are reminding us that they *belong*, as we do, to God, and to the family of God. They are part of the community, based on being-in-relationship, as we are part of the community. They are saying *do not forget this.* This brings me back to my own "awakening" to the depth and breadth of pastoral ministry through the gifts of the church. The very thing these people are witnessing to the church – or perhaps, more specifically to me – is the need to reclaim our mutual humanity, which is rooted in God, and to reclaim our relational community, which is centred on God.

In my quest to understand the nature of personhood, I came across a story, in an article by John Swinton, that I feel compelled to share. It is a powerful illustration of the human need, and longing, to be-in-relation all of our days. The story is told as seen through the eyes of Margaret Hutchison, a Care Home Nurse.

> "An elderly lady suffering from dementia, paced the corridors of the nursing home restlessly – repeating over and over, just one word. The staff was disconcerted, but no one seemed quite sure how to calm her and put her mind at rest. In fact they were at a loss to understand the reason for her distress. The word she repeated over and over again was *God* – and that was all she said. One day a nurse got alongside her and walked with her up and down the corridors until eventually in a flash of inspiration she asked the lady, "Are you afraid that you will forget God?" Yes, Yes! she replied emphatically. The nurse was then able to say to her, "You know even if you should forget God, He will not forget you. He has promised that." For this lady who was forgetting many things, and aware if it, that assurance was what she needed to hear. She immediately became more peaceful,

> and that particular behaviour ceased. She was responding positively to care which extended beyond the needs of the body and mind – care of the human spirit". [liii]

This poignant story, of an elderly woman's struggles in the face of dementia, is a wonderful parallel to the story of my parishioner, John. Yet, this story also reveals a profound revelation about this sustaining love of God which reaches beyond memory and beyond our ability to communicate in a way that is cognitively understandable. We are indeed persons called to be-in-relation and, in many ways, who we become is often shaped by the very people we encounter. But, as Swinton reminds us, this identity has a greater dimension, "ultimately our identity as persons, our hopes and possibilities for the future, is determined and sustained by God who, in Christ is with as and for us even, and perhaps particularly in our darkest hour of need. Even when all of our faculties are taken from us, we remain persons-in-relation through God's continued desire to relate to us, to minister to us and be with us now and for ever more. This is an inevitable and beautiful consequence of being made in the image of a Trinitarian God who is *pro me."* [liv] This is what it means to be human.

Again we may further wish to ask, what does this image look like? Looking through the eyes of those with dementia the quest of this sacred journey thus far, has required an acknowledgement of the severity of losses often accompanying this disorder. Many schools of thought have produced a litany of losses which a person can look forward to should they happen to succumb to Alzheimer's disease. We have reflected on loss of cognition, loss of mobility and in most cases, severe loss of memory. In addition, earlier

schools of thought have adopted a definition of "being human" based on cognitive levels as measured by the Stanford-Benit intelligence ratio. Still others have influenced our understanding of being human through biomedical profiling. One recalls reflections, encountered earlier in our search, in this paper, from persons such as Joseph Fletcher, who described the basis for personhood.

> "To be a man we must be capable of self-awareness, self-control, have a sense of time, futurity and past, be capable of relating to others, show concern for others, be able to communicate, exert control over our existence, be curious, be open to changes, have proper balance of rationality and feeling, and have a unique identity. Negatively, men are not any of the following: anti-artificial, essentially parents, sexual, worshippers, or a bundle of rights". [liv]

These cognitive and biomedical based approaches determine our eligibility to belong and our value as persons by measuring abilities against perceived disabilities. The *theological* discovery of personshood, however, does not. Instead, we move away from losses and the potential loss of self - towards the *rediscovery* of self – through a renewed understanding of the presence of the Divine.We see this being lived out countless times in our faith story. Scripture reminds us of encounters that God has had with his people to remind them that their journey does not take a solitary route. When Jesus said, in the Gospel of John, "Behold I have come that they might life, and have it in abundance" it was a reminder, for those who often find themselves on the fringe of society, that they still have a place with God. One could also offer that such a place is found "here and now", within the embrace of a living community of faith that operates and lives out its practices in accordance with this Divine mission.

A similar message of hope may be found in the final verses of that same Gospel. Here we discover a truth that resonates clearly from a God who is with us. In verse 21:18-19 Jesus is says to Peter, "Feed my sheep, I tell you truth, when you were younger you dressed yourself and you went where you wanted; but when you are old you will stretch out your hands, and someone else will dress you and lead you where you do not want to go". Jesus is prophesying the eventual circumstances of Peter's life, prior to his death. Yet, we also can see this as a reflection of the circumstances of those who reside in the world of dementia. When it is no longer possible for us to serve God in the manner in which we once did; when we can no longer even remember who God is or what God has done for us in Christ, God comes along side us and ministers to us in our weakness. Furthermore, our faith journey has reminded us that underneath these truths is the reminder that God coming-to-us in our weakness does not occur as some form of reward for meritus service – for this would remove us, then, from a personhood based simply by *being.*

We have a hope that has moved us beyond this perception. It is found in the very life - force that bases our identity in the way of love. Again, John Swinton offers additional substance to this Good News by reminding us that the acknowledgement of our personhood is "a return to the understanding of an act of Graceful friendship. The inevitable outcome of Christ being *pro me* in ways that cannot be destroyed by the ravages of time or disease, furthermore which also cannot be measured through some other non-divine means....God's coming to us in our weakness, His remembering us when all seems to have been forgotten is an inevitable outcome of his essential nature as

Christ-for-us, Christ *pro me*."[lv]

In light of these reflections it would seem that the most natural "next step" would be to reconnect with this proclamation. In our journey to find a deeper way of caring for persons with dementia we have found that their sense of personhood is reclaimed and sustained through meaningful relationship with God. It is also sustained, however, *through other persons*. This is the very theological foundation which assists *us* in our daily encounters with life and all of its wonders, and is no less so for the person with dementia. We become, come-to-be, persons through our relationship with God *and with one another* despite disease or disorder, despite loss or impairment. The very care offered, if it is to truly to be called "care" – must be shaped by this reality. This is what brings us into the realm of authentic personhood.

The power of this reality, however, is only activated when it is lived out. The Christian tradition has a rich history of being able to offer levels of care and outreach to those in need. We have seen the church take an active role in health care systems, and influence societal mandates regarding the care and support of its citizens. Furthermore, the church maintains that, in Christ, God has come among us with the renewed mission that God's Kingdom is not only a future reality, but here now, in its full expression, for the whole human family. This is our hope and belief. However, this hope must find expression in our practice, particularly in face of society's ever present reality of people feeling as if they've been forgotten by us, or worse, forgotten by God. This is where we have something to offer, the reacquaintance with what it means to be human; specifically, the

entering into a place of recognition, respect and trust for each other. In this understanding, personhood is not a personal attribute nor does relate to the presence or absence of a particular function. Instead it is the product of a particular relationship encounter – between ourselves and the living God.

The questions that have informed my journey have been posed in light of profound relationships with remarkable people who happen to suffer from a very strange and difficult disorder. Their journeys have been fraught with uncertainty and have put tremendous emotional strain on family and friends. In seeking answers to my questions, I was invited to witness their personal struggles to maintain some form of connection with the very pulse that gives them life. Though our walks have differed, our journey's destination has been the same – to know where our place is and who we are in the midst of that. We achieve this by allowing one another to remain as viable members of the Christian community and to have the expression of that lived out through faith in the Triune God. A path that leads to personhood, and a sense of self, cannot exist without each other. As Archbishop Desmund Tutu once said "A person is a person though other persons. I am human because I belong". The personhood of all people in an ever present reality – even in the world of dementia. The relationships we establish, the hope we proclaim, the shape of the liturgy, and the reconnection to the power of the various gifts of the church all help to facilitate this. May this journey continue.

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SURVEY QUESTIONAIRE

1. What is the size of your present congregation? (How many names are on your present parish list)?

2. How many services do you have during the week?

3. Does your congregation have: (check all that apply)

a) Lay Assistants ____
b) Curate ____
c) Associate / Retired Clergy ____
d) Parish Nurses____

4. In your present ministerial context, how many Care Home Facilities do you presently have pastoral oversight?

5. Of the people in care homes, how many do you have a direct personal ministry to? i.e. Parishioners?

6. When offering pastoral ministry to residents in care home facilities, do you: (check all that apply)

a) Offer a hymn sing ____
b) Offer Holy Communion____
c) Offer Scripture readings____
d) Offer other devotional material (Please specify _____

7. If you offer Holy Communion in care home facilities, which form of service do you use?

a) The Book of Common Prayer ____
b) The Book of Alternative Services____
c) Another alternative form (please specify)_____
d) All of the above____

8. If you offer a communion service, is it your practice to:

a) Use Reserve Sacrament ____
b) Consecrate the Elements during the Service ____

9. What are your reasons for choosing to consecrate or not?

10. Do you offer parts of the service where the congregation, in the Care Home Facility, can participate in?

Yes_____ No____

11. When you offer pastoral ministry in Care Home Facilities, do you wear vestments?
Yes_____ No_____

12. If yes, on which occasion would you wear vestments?

13. If yes, which vestments do you wear? (Please check all that apply)
Alb ____ Chasuble____ Surplice _____
Stole___ Cassock ____ Maniple _____

14. Do you use hymns during a service? Yes___ No___

15. If yes, what is your normal practice?

a) Contemporary hymns from the 1998 "Common Praise". ____
b) Older hymns from the 1939 "Book of Common Praise" ____
c) Another source, i.e. Gospel hymns (please specify)_____

16. How many people with Alzheimer's Disease, or other forms of dementia have you ministered to?

17. Do any of the persons who, to your knowledge who have Alzheimer's Disease or other forms of dementia participate in the liturgy?

a) Yes ___
b) No ___
c) If yes, how do they participate?

18. Do you find any response with persons who have Alzheimer's Disease and other forms of dementia with the use or non use of vestments?

a) Yes____
b) No____
c) Unsure____

19. What physical signs of your ministry do you bring with you whenever you offer pastoral care to persons with Alzheimer's Disease and dementia? (Check all that apply)

a) Bible _____
b) Communion set____
c) Wearing clerical attire_____
d) Other (please specify_____
20. Do you find this helps? Please explain

21. In your experience, do the residents who to your knowledge have Alzheimer's Disease and other forms of dementia, ever join in with any of the prayers or responses during a service?

22. Have you ever noticed any specific responses in persons with Alzheimer's Disease and other forms of dementia whenever a familiar hymn is sung? Please explain

23. What hymns, to your knowledge, elicit the most connection with people that you minister to who have Alzheimer's Disease and other forms of dementia?

24. In your opinion, how do Alzheimer and dementia residents respond when the Eucharist is offered at a service?

a) There is a noticeable connection ____
b) There is less of a connection ____
c) There is no discernible difference____

25. Are you aware of any additional services, rites, hymns or ministry tools that you have noticed which increase the connection that you have with persons with Alzheimer's Disease and dementia? Please specify.

26. When ministering to persons with Alzheimer's Disease and dementia, do you ever establish any physical contact (such as the touch of a human hand) with the person?

a) Yes____
b) No ____

28. In your opinion, does this make a noticeable impact on your visit with that person?

29. Where do you find the area for doing ministry to Alzheimer's persons most effective?

a) Dining room converted into a worship space____
b) An open meeting area such as a living room or tv room _____
c) A designated chapel____
d) One on One_____
d) Other space (please specify) ____

30. Why is the area that you have chosen most effective? (Please comment)

31. Have you noticed any specific gifts that the inclusion of a person with Alzheimer's Disease may have brought to your present congregation? If so, what might they be?

32. What challenges, if any, have you found in doing any form of ministry with persons who suffer from Alzheimer's Disease and dementia?

33. Over all, how would you rate your effectiveness in doing ministry with persons who have Alzheimer's Disease and other forms of dementia?

a) Very effective ____
b) Moderately effective ____
c) Not very effective ____

34. On a scale of 1 to 10, what is your comfort level when you offer ministry to persons with Alzheimer's Disease or other forms of ministry? (One = very comfortable, 10 = very uncomfortable)

35. Would a model of ministry be helpful in increasing your effectiveness in this area? Please comment.

36. Would a workshop in this area of pastoral ministry be helpful if one were provided?

Survey Questions

Questions	Comments
1. Size	
2 Service	➢ 4 not including monthly services in extended care facilities (4)
3. Help	➢ Not formally but nurses in parish (10)
4.Home Care	➢ One care home and 2 seniors residences(7) ➢ None, unless you count St. Pete's Abbeyfield (8) ➢ 2 for worship and one time month only (11) ➢ None specifically (11)
5. People in Care	➢ None presently in care (7) ➢ 13 in care homes, but there is an additional 40 +shut ins (8)
6. Ministry	➢ Parish magazine(1) ➢ Stories relating to readings(they request them and are disappointed if one is not told (4) ➢ Copy of the sermon other occasional printed item (11)
7.Book	➢ BCP Abridged (6) ➢ From past experience (9) ➢ BCP- shortened (10) ➢ See attached (11)
8. Sacrament	➢ Reserve sacrament deacon and lay eucharistic ministers – consecrate –rector (8)
9. What are your reasons for choosing to consecrate or note	➢ The words of liturgy are familiar, reassuring & are deep in long term memory. Using KJV also is a comfort especially during the Christmas Season (1) ➢ The residents are unable to manage a lot of spoken work and cannot cope with long services. Also it has been the "tradition" in these facilities. We use more music than anything else as this energizes and seems to connect with the residents 0 we have excellent musical resources.(4) ➢ I'm a priest so I do it (5) ➢ Time is the main factor & Residents often have a very short window that is schedules and we don't get a large enough window to do a service with full consecratory prayer./ Also the residents themselves tire quite quickly (6) ➢ Convenience and time – keeps serve to 15 minutes (7) ➢ Personally,, I choose to do so, as the recipients appreciate the words of consecrations. I tend to shorten the BCP service somewhat (8) ➢ Level of cognition (9) ➢ These are high functioning senior more "the" church (11) ➢ Involves people in celebration otherwise emotionally spiritually they can perceive (wrongly)

Survey Questions

	that they get the "leftovers" (12)
10. join in	➢ Saying some prayers (7) ➢ For Abbeyfield only, otherwise we visit each shut-in individually (8) ➢ They set up, take the offering help choose hymns and very occasionally read (11) ➢
11. vestments	➢ Yes for services, no for communion in individual rooms (5) ➢ I am also the guitar player so I put on a stole, if some else did music I would wear full vestments (11)
12. if yes, on which occasion would you wear vestments	This question was missed by all participants in the survey.
13. what is worn	
14. hymns	➢ From past experience (9)
15 source of hymns	➢ Songs of the Faith Anthology – I would prefer other resources but this is their choice (4) ➢ I pick hymns I know residents know and I prepare LARGE PRINT copies of distribution, older hymns from "Common Praise" and "Jesus Loves Me"(5) ➢ Songs of the Faith Anthology (6) ➢ What is used in the facility (9) ➢ 2-3 hymns, SGP(10) ➢ From "songs of the" Faith Anthology" and" Hymns we love to since"(11)
16.numbers	➢ Many I'd say 12 – 15 in the last 5 years (5) ➢ Currently two - several over the years (7) ➢ Probably 6 personally and more indirectly thru taking services in homes in the past (9) ➢ Over a lifetime of ministry – lots – not too much right now (11)
17. participants	➢ Yes, through music hymns, especially well known refrains form certain hymns.(4) ➢ Sing or tap food to music of hymns recite Lord's Prayer, and other parts of liturgy with me(5) ➢ Usually singing if they know the hymns and also with prayers like the Lord's Prayer, confession (6) ➢ They have service memorized, they cross themselves, they thank me for coming (7) ➢ Fully for now, but they are slipping (8) ➢ Hymns – Lord's Prayer (9) ➢ Singing hymns (I usually use only verse 1 or 2 of well known) joining in with prayer (11) ➢ To their ability, depends how advice disease is
18. response	➢ No- I find clericals are enough – extra vestments seem to create anxiety in some (4)

Survey Questions

	➢ I think they like them it seems more like church (7) ➢ In the past, we have had Alzheimer's patients who were in the terminal stages of this disease, vestments didn't seem to be relevant (8) ➢ I find the use of vestments helpful especially if I go around and show beautiful they are and let/invite people to touch them and remember (11)
19. signs	➢ Consistency (same people) similar program the "table" acts as an owned "symbol" – the movement of the table to become a "sacred space" to routine and becomes an unthreatening focal point (4) ➢ BCP Red Book (5) ➢ Prayer Book – BCP and or BAS (6) ➢ Prayer Book (7) ➢ BCP sometimes, hymn book sometimes (11)
20. do you find this helps? Please explain	➢ I believe it helps my presence as a priest with clear and evokes long term associations – less explaining as to who I am and what I do (1) ➢ Definitely, with familiar prayers, liturgy and actions (2) ➢ Yes of course!, Physical objects are not abstract. Dementia takes abstractions before the physical (5) ➢ Yes, they seem to respond better to symbols they can identify clearly (6) ➢ Definitely, it gives structure and they know who I am (7) ➢ Blair, I assume you are referring to the conduct of a full service at a hospital bedside. It is hard to judge because our ministry is molded to the individual patient and ability to comprehend (8) ➢ Yes, they recognize from past experiences especially the collar (9) ➢ As above with vestments (11) ➢ Patients are looking for "connections" symbols offer something they can relate to from prior memories (11) ➢
21. In your experience do the residents with A join in prayers or responses	➢ Yes, if only Amen or consignation(1) ➢ Yes- responses and Lord's prayer (3) ➢ Yes especially the Lord's prayer, or phrases from the choruses of familiar hymn (4) ➢ See above – LP, prayer of humble access, Sursum Corda and the response"--- and with thy spirit (5) ➢ Yes, As mentions, Lord's Prayer, Prayer of Confession, Prayer of Humble Access, Nicene/Apostle's Creed (6) ➢ Yes (7)

Survey Questions

	➢ In the last stages, never, In the earlier stages, always. When I was the curate at St Andrew's we held a formal service at Sidney Intermediate Care Home. We visited, sang and had BCP Eucharist, Yes, some of the old dears would respond to music and favourite phrases in the Bible and BCP (8) ➢ Lord's prayer and Amen (9) ➢ Yes, particularly "old" familiar ones, standard Lord's Prayer, BCP responses.(10) ➢ Yes, especially in well known prayers and less with responses – they seem to need "start-up" and "memory Trigger" time (11) ➢ Yes, unless illness advanced (12)
22. any specific responses in persons with a familiar hymn	➢ I find greater awareness and participation(1) ➢ Also singing with and maintaining eye contact (4) ➢ See #17 (5) ➢ Yes, I have seen one or two completely uncommunicative patients, join in a hymn singing from memory and later lapsing again into silence (8) ➢ They will sing, mumble or hum (9) ➢ Smile, movement to music (10) ➢ Deep attention and less agitation (11) ➢ Occasionally it really connects in their memory and brings joy or other connections wedding baptisms etc. (12)
23. what hymns elicit the connection with person with A	➢ Christmas Carols and Wesley Hymns (1) ➢ Any that they know /remember (2) ➢ Tell me the Old Old Story, Give me Joy in My Heart, Blessed Assurance, In the Garden, L love to tell the story, Amazing Grace, Praise, why soul the King of Heaven (4) ➢ Onward Christian Soldiers, O Go Our Help in Ages Past, Holy, Holy, Holy, The Lord's my Shepherd, Christmas Carols, Jesus Loves Me, Amazing Grace, Tune Crimond, All People that on Earth Do Dwell (5) ➢ I cannot recall specific hymns, however, it was usually hymns learned in childhood.(8) ➢ The older ones (9) ➢ Jesus Loves You (10) ➢ Lord is my shepherd, Christmas Carols, Abide with me (11) ➢ The popular when they were children, " there is a green hill" Jesus loves me" and "The Old rugged cross"
24. response	➢ It does depend on the distractions, the familiarity with the space, and the people assisting. The act of receiving for those in stage 1 &2 is clearly meaningful. But later on there is no obvious

Survey Questions

	connection.(4) ➢ Well – until they don't ever know that the wafer is to be eaten – late stages of dementia – all 3 of your stages, depending on how severe the dementia (5) ➢ More often than not, but on occasion they seem not to respond at all (6) ➢ Again Blair, if the person is in the last stages and no longer has speech, then they don't participate, But they will consume a portion of a wafer dipped in the wine (8) ➢ Most want it some cannot seem to comprehend, caring staff can help discern (10)
25. are you aware of any additional services rites etc	➢ Stories that connect to earlier life experience especially ones that can evoke sensory memories ie. Smells, tastes, colours (4) ➢ Some like me to touch them, cover their hand with mine. (5) ➢ They like to recite the Lord's Prayer (7) ➢ The "ministry of presence" is much under related as family and friends "assume" that old George or Sally don't' recognize them or what is happening. I never talk down to them but include them fully.(8) ➢ They respond to outstretched hand for a handshake(9) ➢ Saying Lord's Prayer, and Psalm 23 together even at a visit/away from worship !11) ➢ Depends on their denominational background candles for the 'Altar" set up work, for T.C> Anglican, Lutherans, but seem threatening to Mennonites' etc.(12)
26. contact	➢ Rarely – unless a long term pre-existing relationship (4) ➢ Oops, see above (5) ➢ Limited to shaking hands (6) ➢ I shake their hands as they leave the service area (7) ➢ To the shoulder or head (8) ➢ Yes (9) ➢ I always in a service, include the sharing of the preach, to get volunteers engaged too (11)
28 does touch make a noticeable impact	➢ I feel at very least there is a momentary comfort brought ;for 7 years I ministered to Yvonne who, always, it was the first time she had "met" me, I believe for that hour or so, she felt a little comfort at attending service and sacrament (1) ➢ Yes, of course (5) ➢ I think that sort of comfortable and appreciate contact does make a difference; sometimes if to nothing else than contact does have an impact on the visit. (6) ➢ Yes touch (appropriate touch 1.e) is always welcome. I believe that everyone, who is imprisoned with dementia, still has an innate sense of being. That is I believe they know they are alone or they are with someone, who cars. This is still one of our Lord's gifts " and Lo, I am

Survey Questions

	with you always, even unto the end of the age"(8) ➢ Yes (10) ➢ Yes, The sharing of the Peace changes whole tone of the day, a touch by one is more individual in timing place of touch and occasion of touch, sometimes it appears to be unwelcome (11) ➢ Yes, only a few are so ill that all mental function/recollection has gone
29 where	➢ Usually no choice where I can hold service usually a dining room (1) ➢ Area not so important (3) ➢ What is familiar to them and consistency (4) ➢ A well set up space with little or no distraction noises (10) ➢ One on one, rec9ommend caut9ioon, makes minister vulnerable to false accusations, first chapel second opening meeting area and third dining room (12)
30. Why is the area that you choose most effective?	➢ It is known as a meeting place – familiar (2) ➢ They has been choice offered usually it is the largest space available (4) ➢ Chapel associations are a help, I suppose one on one necessary for advanced stages (5) ➢ I think the context helps remind of worship and church related open spaces, where meeting a member of the clergy would make sense as opposed (6) ➢ A public space but one they do not normally use (7) ➢ If hospitalized, the parishioners usually has lost neuro-motor skills and is therefore confined to a bed.(8) ➢ Chapel, recognition quiet, not so busy (9) ➢ Distraction is very noticed, visual is important, we once had someone do a liturgical dance with red banner during Clinical Pastoral Education, very effective (10) ➢ Continue best focus familiar (11)
31. any gift A disease brought to congregation	➢ They are present and by being there show all are important (1) ➢ The gift of needing lover – brings people together (2) ➢ Opportunities for ministry to challenge how we include people (3) ➢ When accompanied by a nurse of other companions (sometimes family) other parishioners appreciate the witness of one who participates at a different level, also seeing an old family friend (5) ➢ Tolerance and patience (7) ➢ The two still with us are slipping, but slipping with difficulty. They are much loved and profit from that love (8) ➢ Brings out compassion in others (9) ➢ It presents that in individual in a more normal way, in context of "not normal" place (11)

Survey Questions

	➢ Frustration when understanding or comprehension is absent (12)
32.what challenges?	➢ Occasional disruptive behavior ➢ Keeping it meaningful for them, not me(5) ➢ The challenge I find is to make the connection and find the response sometimes very subtle. (6) ➢ Inappropriate comments – they keep repeating themselves (7) ➢ I believe that my parishioners ARE my family and it hurts to see blood relatives grieve twice – once as they lose their loved one to this insidious disease and again as physical life ends. (8) ➢ Was suggested at school, we do away with standing to sing etc. sit in solidarity without friends (10) ➢ Learning how to slow pace, reduce words, use triggers, not worry! (11)
33. effect	➢ How do you measure this? Levels of agitation. Levels of participation, connections, if it is a sense of connection then – moderate on a good day (4) ➢ I think over time I have become more effective I think there is a way to go yet!(11)
34. comfort	➢ 5 – I am not used to it and don't know enough to feel entirely at ease (6) ➢ 2-3 Sadly there is at the end little feedback from the patient. However, it is crucial that we are trained to work with our parishioners as they descend further and further into dementia! (8)
35 model	➢ Knowing sure easy applicable strategies would be of help in boasting effectiveness and self confidence(1) ➢ Maybe in the future, we are focusing our energies on families not seniors (2) ➢ Not really(3) ➢ The more we can understand about this type of spiritual developmental stage and how we can best support and nurture, the better (4) ➢ Sure – the more we have to draw form the better (5) ➢ Yes I think the experience is very important but having direction and guidance is the difference to making that experience effective or not (6) ➢ Yes, but this is not priority for me (7) ➢ Yes, especially more clinical knowledge of the disease and its stages and varieties (9) ➢ Chapel space in nursing homes (10) ➢ Yes, keep up with learning about the real changes in perception, memory etc, in our growing population of frail elderly (11) ➢ Likely not because there are so many variations eg. How ill they are what is their religious background (12)
36 workshop	➢ Not for me in my current work (3)

Survey Questions

	➢ Yes, - get in touch with Nancy Ford and offer it through the Diocesan Pastoral Care Committee (5) ➢ Absolutely, at Seminary we only touched on this specific disease, but we live longer and more cases are arising (8) ➢ I am sure some would find useful, particularly lay Pastoral Care Workers, (12)
Other comments	➢ Blessing on your work old friend! (8) ➢ Note- q16 on are unanswered from my experience with elderly with dementia 1-15 present ministry (11)

Survey Questionaire

	A	B	C	D	E	F	G	H	I	J	K	L
1	Form No.	1. Size	2. Services	3. Help	4. Home Care	5.People in Care	6. Ministry	7. Book	8. Sacrament	10.join in	11.vestments	13.what is worn
2	1	400	3	a ,c	1	5	a,b,c,d	a	b	yes	yes	alb stole
3	2	150	1	no	0	na	na	na	na	na	na	na
4	3	na	2	na	0	0	na	na	na	na	na	na
5	4	150	4	b,c	3	85	a,b,c,d	a	a	yes	no	na
6	5	667	6	a,c	4	15	a,b,c	a,b	b	yes	yes	alb stole
7	6	180	5	a,b,c	2	1	a,b,c	a	a	yes	no	na
8	7	100	2	c	3	0	b	a	a	yes	yes	sur,stole,cassock
9	8	250	4	a,b,c,d	0	13	a,b	a	a,b	yes	no	stole
10	9	100	2	a,c	0	1	b,c	b	a,b	yes	yes	stole
11	10	na	na	a,b,c,d	3	4	a,b,c	a	b	yes	yes	stole,alb
12	11	42	1	a,c	2	2	b	c	b	yes	no	alb,stole,chasbule
13	12	120	2.5	a,c	0	2	b,c	d	b	yes	no	na
14	13	150	a	2	22	a,b,c	a	a	a,b	no	yes	alb, stole
15	14	320	6	a,c	3	20	a,b,c	a.b	a.b	yes	no	na
16	15	300	1	na	4	29	b,c,d	c	b	no	yes	stole,cassock
17	16	255	3.25	c	3	2	a,b	a	b	no	yes	stole
18	17	300	6.5	a,c	0	7	b	b	b	na	no	alb,stole,chasbule
19	18	na	3	a,c	4	1	b,c	a	b	no	no	na
20	19	403	8	c	2	6	a,b,c,d	na	b	yes	no	collar
21	20	130	2	a,c	na	na	na	na	a	na	na	na
22	21	90	3	c	3	nas	a,b,c	a	b	no	yes	alb,stole
23	22	200	3	a,b,c	3	6	a,b,c,d	a	b	yes	no	na
24	23	690	23	a,b,c	8	2	a,b,c,d	a	b	yes	yes	alb,stole
25	24	200	2.25	a,c	4	10	b,c,	b	a,b	yes	yes	stole
26	25	235	1	a.c	4	12	a,b,c,d	a	a	yes	yes	stole
27	26	na	na	na	na	na	na	na	na	na	na	na
28	27	150	2	a,c,b	4	3	b	b	a	yes	yes	stole
29	28	177	1	a	1	0	a,b,c,d	b	b	no	ni	na
30	29	400	4	a,b,c,d	3	10	a.b.c	a.,b,c,	a,b	yes	yes	alb,stole
31	30	400	3	a,c	2	5	a,b,c,d	a	b	yes	yes	stole

Survey Questionaire

	A	M	N	O	P	Q	R	S	T	U	V	W	X
1	Form No.	14. hymns	15.from where	16. numbers	17.participates	18. response	19. Signs	24 Response	26 contact	29. where	33.effect	34 comfort	36 workshop
2	1	yes	b	6	yes	yes	b,c,d	c	a	d	b	5	yes
3	2	na	na	75	na	yes	c	b	a	a	a	3	yes
4	3	na	na	12	yes	yes	a,b,c	a	a	na	b	2	no
5	4	yes	c	40	yes	no	b,c,d	a	na	na	na	8	yes
6	5	yes	c	12	yes	yes	a,b,c,d	na	a	c,d	b	2	yes
7	6	yes	c	12	yes	c	a,b,c,d	a	a	b,c	b	5	yes
8	7	no	na	2	yes	yes	a,b,c,d	na	a	b,	b	5	probably
9	8	no	na	2	yes	c	a,b,	b	a	d	b	2	yes
10	9	yes	b,c	6	yes	c	a,b,c	a	a	c,d	a	1	yes
11	10	yes	c	na	na	na	na	a	a	c	b	3	yes
12	11	yes	c	0	yes	yes	b,d	a	a	c,d	b	1	yes
13	12	yes	b	many	yes	no	a,c	b	a	a,b,c	b	3	for lay assist
14	13	no	na	4	no	c	a,b,c	a	a	d	a	2	yes
15	14	yes	b	15	yes	c	a,b,c	a	a	a,c,d	b	5	na
16	15	yes	c	55	no	no	a.b	a	a	c,d	c	5	no
17	16	yes	b	na	yes	no	a,b,c,d	b	a	b	c	1	yes
18	17	yes	b	14	yes	c	a,b,c	na	a	d	a,b,c	3	yes
19	18	no	na	dozens	yes	no	a,b,c	b	a	b	b	6	yes
20	19	yes	b,c	30	yes	c	a,b,c	a	a	b,c.d	b	1	na
21	20	na	na	na	na	na	b,d	na	na	na	na	na	na
22	21	yes	c	25	yes	c	a.b.c	a	a	b	b	1	yes
23	22	yes	c	1	yes	no	a,b,d	a	a	c.d	b	8	yes
24	23	yes	na	24	yes	yes	c,d	na	a	a,d	b	2	maybe
25	24	yes	c	0	yes	c	a,b,c,d	a	a	b,d	b	1	yes
26	25	na	na	na	a	yes	b,c,d	a	a	d	c	8	yes
27	26	na	na	na	na	na	na	na	a	na	a	1	na
28	27	yes	c	na	a	c	a,b,c.d	a	a	b	b	3	maybe
29	28	yes	b,c	4	no	c	a,b,c	a	a	a	b	8	yes
30	29	yes	c	na	yes	yes	a,b,c	a	a	a,b,c,d	a	1	na
31	30	yes	c	3	b	b	a,b,c	a	a	a,b,c,d	a,b	1	yes

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